A Happy New Year to all our members!

INTRODUCING OUR NEW BTF PATRON, JOSEF CRAIG!

The swimmer Josef Craig is our newest British Thyroid Foundation Patron. Josef, who swam to gold at the summer Paralympic Games in London last year and broke two world records, was diagnosed with Graves' disease in 2011. It could have put paid to his chances of being selected for the British team but instead it spurred him on even more to get well and fit again.

In an interview with BTF Editor Judith Taylor (who was a Gamesmaker volunteer reporter with the Paralympic News Service during the summer) Josef and his mother Kim talked about his thyroid disorder and his fight back to fitness.

Josef, 15, from Jarrow, has mild cerebral palsy. He was introduced to swimming when he was nine and began competitive swimming a few years later. He trains at South Tyneside Swimming Club.

In 2011 he was training with the goal of being part of team GB at the Paralympic Games in Rio in 2016 when he was diagnosed with Graves' disease.

Josef: 'I have a monthly weigh-in at the gym and one month my weight had gone down by five kilos which is substantial even though I was eating more than usual and eating crazy food. The doctor recommended I went for blood tests.'

Kim: 'Jo was getting tired regularly but we put it down to growing pains. The doctor rang with the blood test results and explained his thyroid was over-active and that he should stop training until it was under control. It took a while to sink in and then I had to tell Jo he couldn’t take part in the competition he was training for.’

Josef: 'When my thyroid was diagnosed I felt shocked. At first I wanted to ignore it and carry on swimming but I was starting to have heart flutters. It was scary!' ‘In hindsight there were other symptoms. I got a bit low and depressed at the Scottish nationals a month before I was diagnosed. I was following a strict regime but I couldn’t sleep even though I felt shattered so I was a wreck the next day. I was off my times and couldn’t control my emotions, and I was upset and angry.

‘I was upset to have to cancel a competition but I said to myself if I get sorted I’m going to push myself harder and go for the London Paralympics!

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The BTF launched a film about thyroid disorders for children at the British Society for Paediatric Endocrinology and Diabetes meeting in Leeds. For the full story see page 8.

Josef pumps his fist in celebration after winning gold in the S7 400m freestyle at the summer Paralympics
Jofe was prescribed Carbimazole for a short time but he said that while he was on it he could go back to training.

**Kim:** ‘The plan was for Jo to stay on Carbimazole for two years but it seemed that most people needed either surgery or radioactive iodine after that way so Jofe asked if he could have treatment right away, and the doctor agreed. Jo had a big say in what happened.

**Josef:** ‘I didn’t know what Graves’ disease was at that time, but the hospital helped me to get to grips with it.

‘I discussed the possible treatments with the doctor and felt personally that it would be best to have radioactive iodine treatment. If I had carried on taking Carbimazole I couldn’t have competed. If I’d had surgery I might have lost too much through the longer recovery time, and there was also the risk of damaging my calcium glands.

‘In British swimming there’s a doctor we went to for advice. He was very culled up and said if there’s any gland you can lose it’s the thyroid gland because it’s easy to replace it with tablets. Now I take 150mcg levothyroxine.’

Josef spent two months in hospital and recuperating at home and then, true to his promise to himself, he set his sights on getting to London. In 2012 he won his first British medal with a bronze in the 100m freestyle at the 2012 British Swimming Championships, followed by four more personal bests. He competed for three S7 events at the London Paralympics last summer and qualified for all three finals, finishing fourth in the S7 100m final and beating his own world record set earlier that day to win the S7 400m freestyle - the youngest Team GB gold medal winner.

A few weeks after his win Josef said: “I am still coming down from a high but I am just so happy and excited.”

He is adjusting to being back at school. ‘All I want to do is get back to normal life. It seems more normal now than it did but it is still weird because people recognise me and come up to me in the street.’

His mother is slowly coming back to earth. ‘It feels surreal! But I’m still his mum.’ She is firmly supportive of Josef’s role as BTF Patron, because she says: ‘If you win you can do so much to help so many people and put disability sport in the public eye.’

So what’s next?

**Josef:** ‘I hope to go to Rio in 2016 if I qualify’ (he says modestly). ‘I hope I can do well there. It will be amazing if I can smash that world record again.’

‘My other sporty young sources is: ‘If you’re diagnosed with a thyroid problem, don’t overdo it. It can be damaging to your health. But stay positive and in control and live as normal a life as possible. It can be sorted if it’s found in time.’

BTF Director Janis Hickey says: ‘We’re very pleased and proud to welcome Josef as a Patron and hope that he continues to come up to me in the street.’

**David Fortune**, a volunteer and one of our new Trustees will be project managing the implementation of a quality management system at BTF HQ.

He says: ‘I have established quality management systems in two small companies I founded, and for another company as a business consultant. I will use my experience and skills to work with BTF staff, volunteers and trustees to ensure:

- analysis of existing procedures and impact of changes;
- effective communication to share knowledge and discuss ideas, provide solutions and make decisions;
- leadership and good team playing to encourage, achieve goals, and to build a culture of taking pride and value of quality management; and
- time management to prioritise tasks and time to achieve the successful completion of the project.

**New role for Trustee**

**Massive congratulations ...**

... to our Patron Josef Craig who was named Young Sports Personality of the Year at the BBC SPOTY awards and was awarded an MBE in the New Year Honours list; and Clare Balding who won wide praise for her television coverage of London 2012. Clare collected the achievement of the year award at the Women in Film and Television awards and Attitude’s TV Personality of the Year award as well as Biography of the Year award!

**Rock Up and Sing!**

Cathryn Perkins has joined the BTF as PR and Events Manager after helping out last year as a volunteer and organising the BTF Crime Writing Competition Do For The Throat in conjunction with The Harrogate Crime Writing Festival.

Josef Craig, the gold medal winning paralympian swimmer who has been a Patron of the BTF (see front page).

**Membership fees**

Despite increased costs we have managed to maintain our membership fees for the fifth year running. This has been made possible thanks to the many kind donations we receive and the funds brought in from our fabulous fundraisers.

We have also introduced a Lifetime membership fee of £200. Please see the back page of the newsletter for full details of membership fees.

**Leaving a legacy**

Gifts in wills play a vital role in funding our organisation and help to sustain the level of research into thyroid disorders that is so urgently needed. Legacies also help us to continue to provide support and information to patients. By leaving a gift you really will be making a lasting difference. We are grateful for gifts of any size.

We will be including more information about how you can help to make a difference in our next newsletter.

**Medication issues**

In the latest issue of the newsletter we asked you to contact us if you had medication issues, and we received several replies. Thank you to all who responded, and also for your kind comments about the **BTF News**.

One of the main issues reported to us is still the **difficulty in obtaining anything other than 28-day prescriptions** - even though you may have previously obtained longer scripts - and how frustrating you find this. The reason frequently given to patients was **PCT ‘guidance rules’ or the local PCT ‘directive’** (you may recall that the Department of Health was keen to make it clear in their response to us in 2008 that there had been no such government directive!).

One member’s GP said he was ‘not prepared to bend the rules’. Wastage of medicine is mentioned as a matter for concern, although levothyroxine is very inexpensive.

One member on alternate day doses of levothyroxine (125mcg/150mcg) had written to her GP to request a prescription length of 56 days’ supply of 100mcg alongside the 28 day supply of 25 and 50mcg. Unfortunately the GP responded by only issuing the 25 and 50mcg levothyroxine strengths in alternate months, but requiring the member to continue to request 100mcg every 28 days.

Issues of quality and subsequent withdrawal of supplies were raised, an area in which the BTF has attempted to provide updates on the BTF website, although this was very much an area of shifting sands. In particular Elexiron came under fire.

One member alerted us to an article in an Israeli newspaper in January 2012 about the problems caused by an upsurge in side effects after the manufacture of Elexiron changed the formula.

Further opinions expressed were that there should be a wider range of levothyroxine strengths available, which would allow fine-tuning of the dose. The BTF is currently in discussion with a manufacturer of levothyroxine about this matter.

**UK iodine deficiency - the way forward**

The UK is now in the top ten iodine-deficient countries worldwide in terms of numbers of iodine-deficient school-age children.

Following a meeting held in London in June last year to discuss the way forward a UK Iodine Status Strategy Group - UKISS - has now been established.

The group consists of:

- **John H Lazarus**, Professor of Clinical Endocrinology and Regional Coordinator International Council for Control of Iodine Deficiency Disorders (ICCIDD) West Central Europe
- **Margaret Rayman**, Professor of Nutritional Medicine and Sarah Bath, Post-doctoral Fellow, University of Surrey
- **Mark Vanderpump**, Consultant Physician and Honorary Senior Lecturer in Diabetes and Endocrinology, Royal Free London NHS Foundation Trust
- **Kate Jolly**, Professor of Public Health, University of Birmingham
- **Janis Hickey**, Director, the British Thyroid Association Annual Meeting in London

Professor Lazarus says: ‘The group held its first meeting in November 2012 to formulate a plan of action, which it will put in place over the coming months.’

**References**

UK is now iodine-deficient says research team. **BTF News 77 September 2011**

Iodine status in the UK: the way forward. **BTF News 81 September 2012**

**TED patient survey**

The BTF is conducting a survey of patients who have been diagnosed with thyroid eye disease in the past 12 months jointly with the Thyroid Eye Disease Charitable Trust (TEDC). Please see the BTF website for further information or email us for a questionnaire: info@btf-thyroid.org. The survey will run until 30 April 2013.

**BTF patient literature review**

The BTF reviews its patient information literature every two years, and revises it as necessary. We are starting the next review this month.

We would like to hear from you about your experiences using our literature and whether you have comments or suggestions about the current Quick Guides and leaflets. Please send your comments to info@btf-thyroid.org or write to head office by the end of March marked ‘patient literature survey’.

The current patient literature on our website is: www.btf-thyroid.org under ‘Your Thyroid’.

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OUT AND ABOUT

BSPED conference 2012

The BTF was invited to have a stand at the 40th Meeting of the British Society for Paediatric Endocrinology and Diabetes (BSPED) in Leeds on 7-8 November.

Julia Priestley writes: There were some really interesting talks that we attended including ‘Iodine Status in UK pregnant women and implications for fetal brain development’ by Dr Sarah Bath, which was actually awarded the BSPED Award for best abstract. There were also talks on the management of hypothyroidism and hypothyroidism that gave us an insight into all the work that is currently being done in the field.

The meeting was an excellent opportunity to meet the paediatric and endocrine nurse specialists who look after children with thyroid conditions every day and to introduce them to our literature. We also gave out over 150 copies of our new children’s animation DVD as well as other BTF materials. (For the background about how the DVD was made see ‘My thyroid broke’ but we can fix it! on page 8.)

Everyone we met seemed to be delighted with the breadth and range of support that BTF now offers for children.

Talking about thyroid cancer

In October, Janet Prentice, BTF Local Coordinator for Birmingham and one of our new Trustees, gave a very successful talk to the Oncology Product Creation Unit of Eisai, which is the National Cancer Institute of Milan talking about RARECareNet.

Statistics show that the UK cancer survival rates are lower than those in the EU so we need to work together to ensure our survival rates improve; this would mean 5,000 more patients in UK would survive each year. Earlier diagnosis and speedy referral to an appropriate specialist unit would improve the survival rates. We need to be prepared to work with EU countries and it is possible that the most appropriate specialist unit may not be in this country. Cross-border healthcare rights for UK patients are therefore of vital importance.

RARECareNet works with various institutions in the UK, the University of Edinburgh, London School of Hygiene and Tropical Medicine and iKLIN and it wants to involve patient associations going forward.

RARECareNet aims to build an international network to provide comprehensive information on rare cancers to the community at large.

In the afternoon nearly 80 people attended Cancer52’s second annual briefing at the House of Lords. Attendees included a mix of stakeholders in the rare and less common cancer community from industry, governmental bodies, partnership organisations from the UK and Europe and many of Cancer52’s charity members.

The briefing was hosted by Baroness Delyth Morgan who is Honorary President of Cancer52 and the other speakers were Professor Sir Mike Richards, CB, National Clinical Director for Cancer at NHS England, Dr Sam Groth, Cancer 52, and Dr James Larkin, Clinical Oncologist from the Royal Marsden.

Speeches covered many topics from early diagnosis to the need for drugs that could control and perhaps even cure the cancers that have spread, to highlighting the continuing challenge that no national cancer initiative should exist without a rare and less common cancer perspective.

Thyroid Cancer Alliance goes to Pisa

The Thyroid Cancer Alliance met at the annual European Thyroid Association conference, which was held in Pisa, Italy on 8-12 September. The European Thyroid Association (ERTA) is a professional organisation of researchers and clinicians in Europe who meet every year to present their latest results. The ERTA is represented in the Alliance by Judith Taylor who is also the ERTA Secretary.

Judith writes: This was only the second time that the Alliance had met and was the first time for Alliance members had attended a professional medical meeting together, and for several members it was the first medical conference they had attended.

The ERTA kindly provided us with space to exhibit information about the Alliance and to display information on behalf of the Alliance member organisations. It was an excellent opportunity to meet thyroid specialists to discuss patient support(s) in their countries and for them to learn more about our own organisations. While there are many patient organisations providing information and support to thyroid cancer patients, there are many countries around the world where there is no organised peer support.

During the conference we held our Annual General Meeting and I, Kate Farnell (Thyroid Cancer Support UK) and Helen Hobrough (Thyroid Association meeting in Pisa with Dr Clive Harmer, Helen Hobrough (Wales), and Amelia Concera (Spain).

Let the SON shine!

On Friday 9 November the Dutch Thyroid patient organisation Schilzwangerschap Nederland (SON) celebrated its 25th anniversary with a patient conference in Utrecht. The SON is a patient run and patient led organisation run by thyroid patient organisations who have decided to join forces to share resources. BTF Editor and Trustee Judith Taylor who has worked for over 30 years in Holland and spends about half her time there is a member of the SON and was at the conference.

Judith writes: The day-long conference was held in the Jacobkerk in Utrecht. It was attended by around 800 people and was fantastically well organised with an excellent line-up of both professional medical speakers and patients. A nice touch was the SON gift blanket on each chair for delegates to take home with them. Fun and practical Churches are often chilly even if you’re not hypothyroid!

The topics included nutrition, thyroid cancer, the quality of thyroid patient care, thyroid eye disease, managing hypothyroidism, and T3-T4 combi therapy.

There was a particularly interesting presentation about the thyroid hormone T3 and patients with thyroid eye disease who have been recommended to have surgery. These clinics are only held in the Netherlands, but there are now some in London and London.

Towards the end of the conference two clinicians presented the pros and cons of whether to treat patients with a combination of T3 and T4. At the end of their joint session the two presenters ‘unveiled’ the latest guidelines (2012) of the Dutch Internists’ Association which has adopted the view that if a patient does not do well on T4 alone, and provided they do not have cardiovascular issues, the clinician may prescribe T3 alongside T4 for a trial period of three months and then re-evaluate.

It was an excellent and informative day and a great opportunity for me personally to meet people who I had hitherto only corresponded with. The meeting closed symbolically with a rousing chorus of ‘Let the sun shine’ and the sound of 800 balloons being popped simultaneously to celebrate the birth of the new joint organisation.

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 see 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 photographs along with your permission to publish them in the BTF News (subject to space) and on the BTF website.

British 10k Run

We still have places available for the British 10k Run in central London on 7 July 2013. Starting at Hyde Park Corner, the route takes you past Trafalgar Square and St Paul’s to Tower Bridge, before returning along the River Thames. It’s a fantastic way to sightsee! If you would like to apply for a place please call the BTF office on 01423 709707 or go to the BTF website.

British 10k Run

Thyroid and pregnancy - what next?

In November Professor John Lazarus, a former BTF Trustee and member of the BTF thyroid and pregnancy project group, delivered the annual George Murray Lecture to an audience of health professionals at the British Thyroid Association (BTA) conference in London.

The subject of his lecture was ‘Thyroid and pregnancy - the way forward’.

Professor Lazarus made several key recommendations:

First, he reviewed the growing evidence of iodine deficiency in the UK and the effect of iodine deficiency in mothers on the intellectual outcome in children and emphasised the importance of correcting iodine deficiency, which he described as a ‘national scandal’.

Second, he recommended there should be interdisciplinary antenatal clinics to manage thyroid disease in pregnancy. He mentioned in particular the need for women taking levothyroxine to increase their dose or learning they are pregnant. (The BTF and the BTA already recommend that pregnant women increase their dose by 25-50mcg a day.)

Should women who are pregnant or planning to have a baby be screened for thyroid disorders? There is still no agreement among professional organisations with regard to screening recommendations for all newly pregnant women but they do advocate ‘aggressive case finding’ in pregnant women with symptoms or in women with a history of a thyroid disorder.

One recent randomised trial into the usefulness of screening had a negative outcome, but Professor Lazarus reviewed the reasons for this and believes that there are sound reasons to continue the screening debate.

*George Murray (1866-1939) was the first physician to successfully use thyroid extract in hypothyroidism.*
Fundraising and donations continued from page 5

Jenni Brooks ran the Chester Marathon on 7 October and raised £200. She says: ‘I had my thyroid removed nine months ago after being diagnosed with Graves’ disease back in 2007. When my sister persuaded me to do a marathon with her, and people started offering me sponsor money, I thought it’d be nice to collect for the BTF, whose information had been invaluable in helping me to decide to go ahead with the operation.

‘It was a lovely sunny day, and the first couple of hours were great fun. It turns out 26.2 miles is a very long way! I don’t think I’d have got round without my sister Lorraine, who is FAR more stubborn than me, and was determined to get her shiny medal. I’m afraid I locked myself in a portaloo after 22 miles, and didn’t come out until she threatened to topple it over.

‘We finished last, in just under seven hours - a fabulous achievement for two non-runners who could probably have done with a little more training! This time last year I could never have imagined I’d have done it.

‘Everyone’s been so supportive. Thank you, BTF, for all the good work you do!’

Jenni Brooks after completing the Chester Marathon

Jo Shaw has raised an amazing £1,700 running the Robin Hood Half Marathon in two hours 15 minutes on 30 September 2012. She says: ‘I went along to support some friends who were running the 2010 Robin Hood Half Marathon and found myself wishing that I was capable of doing it too.

‘It took another year of half-hearted attempts at running on the roads before, to me before I decided that 2012 was going to be the year that I actually did something about it.

‘Whilst doing a half marathon was a huge achievement for me personally, I also wanted to get something else out of it. I was diagnosed with thyroid cancer in December 2007 and as this is my fifth year anniversary I thought it would be appropriate to try and raise some cash for the BTF at the same time.

‘I can thank enough the generosity of those who sponsored me, those who kept me going come rain or shine and my partner John who was OK with the training as long as I was home in time for him to go and play golf!’

Rebecca Roberts completed the Lake Vyrnwy Half Marathon on 9 September 2012 in two hours and seven minutes and raised £135. Her timing was impeccable as she had just found out two days before that her Mum, who had half her thyroid removed in July, had been given the news that the other half was cancer-free so wouldn’t need to be removed.

Jill Liddington and friends

Stephanie Stacey is running the Edinburgh Marathon in May. Her daughter Evelyn was born without a thyroid and Stephanie and her husband Luke have pledged to raise £1,000 a year for us until Evelyn is 16. Luke has already taken part in a sponsored boxing match and other events are in the pipeline.

‘I love walking anyway. But to walk and raise money for something like the BTF so close to my heart made it special. And the best bit was seeing all the messages from family and friends, cheering me on my way. So thank you all!’

Maren Preussler has raised £307 on JustGiving for the BTF. She says: ‘I mainly did the fundraising as I was diagnosed with Graves’ disease about two years ago. At that time I wasn’t aware of how thyroid disorders can affect people’s life. I received a lot of information from the BTF, which helped me to cope enormously. Because you wouldn’t be able to do this without funding, I decided to open a JustGiving page and did a lot of advertising on social media websites. Luckily there have been generous friends of mine and other people who were willing to donate.’

A big thank you to all our fundraisers!

Future fundraisers

Walk for thyroid eye disease!

Dr Dolores Conor. Fight for Sight’s Director of Research, attended the recent thyroid eye disease day in London (see page 14) to describe the annual ‘Carrot Night Walk - See London in the Dark’.

The six- and 15-mile night walks around London bring together supporters of many charities and organisations who have an interest in raising funds for research into eye disease.

This year’s London Carrot Night Walk and proposed regional walks in Birmingham, Cardiff and Glasgow, take place on 20 September.

Jo Shaw after completing the Lake Vyrnwy Half Marathon from 24 August to 2 September 2012 from John O’Groats to Lands End (JOGLE).

Team ‘The NPA JoGLe’ consisted of cyclists Neil, Paul and Andy (pictured above) and support car driver Mick, who are all members of the Centurion running club. The team averaged a very arduous 100 miles a day over undulating terrain and raised just over £1,250 for the BTF!

Steve Robb has completed his series of six half marathons in aid of the BTF, which he decided to do after discovering his daughter Elithid was born without a thyroid gland.

He finished his amazing achievement with a personal best of two hours five minutes 23 seconds in the Aviemore Half Marathon on 14 October. Since the last newsletter he has also completed the Dundee Half Marathon and the Great Scottish Run. In cancer of the thyroid he says: ‘Thank you so much Steve for your dedication!’

Mrs A Di-Vincenzo-Kelly, London raised £40 on a BTF Big Summer Walk.

Jill Liddington and friends

Stephanie Stacey is running the Edinburgh Marathon in May. Her daughter Evelyn was born without a thyroid and Stephanie and her husband Luke have pledged to raise £1,000 a year for us until Evelyn is 16. Luke has already taken part in a sponsored boxing match and other events are in the pipeline.

The BTF has the opportunity to work with Fight for Sight. If you are interested in taking part, and feel able to raise £250, please email: J.Hickey@billy-thyroid.org.uk with the subject header: ‘Carrot Walk’. If we can get together 30 people and raise £7,500, this will be matched by Fight for Sight and will enable ‘Carrot Walk’ to make a difference. Thank you for your donations

Donations

Eric and Georgina Bower donated £50 to mark their Golden Wedding Anniversary. Congratulations and many thanks!

Mrs Margaret Feil donated £200. Mrs J Turner kindly gave £10 for the help she received from the BTF.

Dr Mark Vanderpump and Dr Michael Tunbridge donated royalties of £80.38 from their book Thyroid Disease: The Facts.

Mrs Temple, a long standing BTF member, donated £50 for the occasion of their golden wedding anniversary.

£570 received in memory of the late Margaret Decima May Gillings. Thank you to daughter Mrs E Greenwood.

Desford Lawn Tennis Club donated £85 raised from a raffle it held at a social event in September.

Text to donate

You can now raise money for BTF using a simple text message.

Just text our unique code - THYRO1 - and the amount you would like to donate to 70070.

Thanks to the Vodafone Foundation, the service is completely free of charge on all networks, meaning 100% of your donation will come straight to the BTF!

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Our thyroid broke... but we can fix it!

The BTF has launched a film about thyroid disorders for children. Called ‘Your thyroid broke... but we can fix it!’ the film is now available on the BTF’s website and on YouTube.

Julia Priestley writes: For some time it has been evident through our own research and that of our fellow parents that there is a worrying lack of information for children, and families, living with thyroid disorders. There has certainly been nothing that is specifically child-appropriate.

It was to address this situation, back in the spring 2012, that our former Project Facilitator Donna Reed started a project of producing a film that could be developed into a six-minute animated film to help children aged six to twelve who had thyroid problems, to understand that it is with an over- or under-active thyroid disorder.

Once we had managed to secure funding from the Society for Endocrinology and Betty & Taylors of Harrogate, as well as a generous donation from the BTF, we knew that we could afford to be ambitious. The outline of the project had been drawn up. But it was time to work with Leeds-based digital media agency Numiko (http://numiko.com/) who showed the right voice we also wanted the film to be reassuring, friendly and warm. Children with thyroid disorders might be able to engage with the subject? Would they be scared by the medical stuff? And crucially, would they remember anything useful about the story afterwards?

‘As it turned out, we wore a hit! The kids loved the story and laughed at the funny bits. Best of all, we were surprised - thrilled, if we're honest - by how much even the youngest children remembered about the story afterwards. And they're very normal, either. All the children seemed satisfied that by the end of the story, the two main characters were happy and safe, and understood what was happening.

The ʻstarsʼ of the Numiko film: ʻDoctor Josephine Etterʼ and ʻPatient Little Tomʼ who brought the characters to life with her voiceover. The film was launched at the British Society for Paediatric Endocrinology and Diabetes meeting in Leeds.

We hope people will use to let us have their comments about how useful they found the film and whether they would like to have further support from the BTF.

The film was launched at the British Society for Paediatric Endocrinology and Diabetes (BSPED) meeting in Leeds where we gave away free copies of the DVD to paediatric endocrinologists and specialists. At the feedback we’ve had to date has been overwhelmingly positive. Parents are delighted that finally there is something available that is so child-friendly and the doctors and nurses who’ve have told us they are grateful to BTF for having produced something so eye-catching to hand out to patients.

Some of the comments we’ve received so far:

One mum, Sonia Lewin wrote to us and said:

Thanks for raising awareness of thyroid conditions in children. Our seven-year-old is adjusting to life with a thyroid condition and this awareness is desperately needed. Keep up the good work.

Dr Catherine Peters, Consultant Paediatric Endocrinologist, Great Ormond Street Hospital for Children (GOSH) wrote: ‘Really useful resource for children and young people with thyroid problems. It provides a clear explanation of hypo- and hyperthyroidism and the management of these conditions in a format that will appeal to young people.’

BTF patron Josef Craig said: ‘The film is really funny yet informative and would make getting a diagnosis seem a lot less scary.

Adelle Chapman, of Idle in Bradford, Yorkshire, was diagnosed with Graves' disease in January 2009 when she was 37. She had managed to shift the weight she gained afterwards and had lost a total of four stones with a national slimming club after two pregnancies. She has since trained to become a slimming consultant and took over at Shipley, Yorkshire in July.

A few weeks after reaching my target I found out that I was pregnant with baby number two and this time decided to continue ‘Food Optimising’ throughout my pregnancy. With my thyroid levels under control and my midwife’s consent I managed to stay more in control of my weight gain through this pregnancy only gaining one stone seven pounds, and after giving birth in January I was back to my target weight by August.

Being a Slimming World member isn’t about paying to be told what I can and can’t eat, it’s about getting support to make the right decisions about what food to eat and not depriving or starving myself. Continuing with the group every week means I get great advice from the other slimmers and my consultant. It’s also one hour of the week when I can take some time out from my busy family life to focus on me.

Becoming a consultant seemed like a brilliant opportunity to help people understand that an under-active (or any health issue) does not mean a lifetime of being overweight.

I’m proud of all my members but I especially love being able to help people who have been in the same position as me.

I have several members with thyroid conditions who feel the relief of being able to control their weight at last, but one lady really is an inspiration. After she was told by her doctor to “get using to being overweight” because of having no thyroid and offered drastic treatments she joined my group as a last-ditch effort to lose the weight naturally. She lost a stone seven pounds with the steady one pound a week loss. Less than twenty weeks into her journey she has lost over half a stone and has won Miss Slimmer 2012 award for the person who has most embodied Slimming World and the ‘no calorie deprivation’ is beginning to shine through.”

Adelle’s group meets on Mondays at Shipley Medical Centre on Alexandra Road, Shipley at 5pm and 7pm. For more information on joining her contact her on 07781 383974.

To learn more about Slimming World visit the website

www.slimmingworld.co.uk.
Evaluating cardiometabolic risk in Resistance to Thyroid Hormone (RTH)

Dr Carlos Moran (Institute of Metabolic Science, University of Cambridge & Addenbrooke’s Hospital, Cambridge) who was a recipient of the 2010 BTF Research Award has sent us the following report on her research study ‘Evaluating cardiometabolic risk in Resistance to Thyroid Hormone (RTH)’.

Dr Moran writes: Resistance to thyroid hormone (RTH) is a rare condition that results in high levels of thyroid hormones, but variable resistance to its actions in different tissues of the body. It is most commonly due to an abnormal form of the thyroid hormone receptor - a protein that binds to, and brings about, thyroid hormone action.

Clinical features range from apparently asymptomatic individuals, to those presenting with growth delay and attention-deficit hyperactivity disorder (ADHD) in childhood, or with goitre (enlarged thyroid gland) and/or symptoms of an over-active thyroid in adult life. Making a diagnosis of RTH is not always straightforward and the disorder can therefore remain unrecognised or not be treated correctly. In addition, little is known regarding the long-term adverse effects of this disorder.

Our previous studies suggested that individuals with RTH do not handle glucose normally and have unhealthy levels of cholesterol compared with individuals without RTH. It is known that these abnormalities can, in turn, be associated with increased fat within the liver, stiffer arteries and a predisposition to diabetes, heart disease and strokes. It is not known whether patients with RTH may be affected in the same way. Our study, designed to examine these aspects of the condition in detail.

To date twenty-four patients with RTH have come to our clinical research facility to participate in the study. We have performed comprehensive assessments which have included detailed hormonal and metabolic analyses evaluating the body’s response to a glucose drink, plans to measure the amount of fat and muscle in the whole body and an MRI scan to assess the amount of fat deposited within the liver. We assessed the stiffness of the patients’ arteries by measuring the response of their blood vessels to stimuli which dilate the blood vessels.

So far, we have found that individuals with RTH have higher levels of LDL cholesterol and triglycerides (‘bad’ types of cholesterol) compared with those with normal levels of LDL ('good') cholesterol. They also have higher levels of fat deposited within their liver. We are now process of analysing the results from the blood vessel tests.

We plan to enrol more RTH patients into the study. These studies will, for the first time, provide detailed information on how the presence of an overactive thyroid hormones and partial tissue resistance affects metabolism in RTH.

Eventually, we hope to determine whether RTH patients are at greater risk of cardiovascular problems; if so, it may be possible to target therapies (both with conventional drugs and newer agents) to this patient group.

Our observations may also increase understanding of thyroid hormone action in general.

BTF Research Award 2013

The 2013 Research Award will be in the value of £10,000. 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.

Dr Cheetham writes: The National Thyroidosis Society is looking at how best to administer antithyroid drugs (almost always carbimazole in the UK) to children and adolescents. Recruitment was not as fast as we hoped and we have lost over 80 patients since the study was started. Please let us know if you are in a position to help with this study.

The team at the Royal College of Paediatrics and Child Health is currently recruiting patients with RTH to participate in the study. They are interested in the long-term adverse effects of this condition.

To date twenty-four patients with RTH have come to our clinical research facility to participate in the study. We have performed comprehensive assessments which have included detailed hormonal and metabolic analyses evaluating the body’s response to a glucose drink, plans to measure the amount of fat and muscle in the whole body and an MRI scan to assess the amount of fat deposited within the liver. We assessed the stiffness of the patients’ arteries by measuring the response of their blood vessels to stimuli which dilate the blood vessels.

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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 Portal 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.

RESEARCH UPDATE

Thyroid cells grown in a dish

Skin cell technology may offer a way forward in treating some thyroid disorders in the future. Researchers have found a way to re-establish thyroid function after the gland has been destroyed - at least in mice. Their findings were published online in the weekly science journal Nature in October.

Dr Sabine Costagliola and colleagues at the Free University of Brussels, Belgium first genetically engineered embryonic skin cells to express two proteins that are expressed together only in the thyroid. When these cells were grown in Petri dishes in the presence of thyroid stimulating hormone (TSH), they turned into thyroid cells and spontaneously grouped into follicles similar to those in an intact thyroid gland.

The dish-grown glands were then transplanted into mice whose thyroids had been destroyed with radiation.

Eight of the nine mice treated in this way showed complete recovery - their thyroid hormone levels returned to the normal range.

Writing on the Nature website Dan Jones says that the team plans to use such cells derived from patients with a thyroid disorder, to try to replicate the mouse results in humans, according to the study’s co-author Dr Francesco Antoncic.

Thyrogen approved for expanded use

Thyrogen® (thyrotropin alfa for injection), which is used in the treatment of thyroid cancer, has received European Commission approval for use with a wider eradication dose range. After surgery, patients with thyroid cancer often undergo radioactive iodine (RAI) treatment to ablate any remaining thyroid cells. Thyrogens is sometimes used before RAI therapy to assist in determining thyroid replacement therapy.

According to a statement by the manufacturer, Genzyme (a Sanofi company), the revised indication provides clinicians with the option to give a lower dose of RAI. Previously the amount was specified at 100mCi, whereas physicians may now select a dose from the range of 30 to 100mCi.

The decision to expand the approved indication is based on the results of two large studies (HIo and ESTIMABLE) which were published earlier this year.

Low doses of RAI were well tolerated in both studies. In both studies, patients receiving Thyrogen rather than withdrawing from thyroid medication had fewer hypothyroid symptoms and better preserved quality of life.

Genzyme has also announced that the supply of Thyrogen has been fully restored. As a result, Genzyme says it is able to supply all patient demand globally.

MEDICINES UPDATE

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The third study is the British Paediatric Surveillance unit study, which is looking at the incidence of congenital hypothyroidism in the UK and how paediatricians manage the condition initially. This has been under way for a year and we are now halfway through where we can start analysing some of the results. This study is supported by the Royal College of Paediatrics and Child Health and received backing from the BTF.


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

Please address general letters to: the Editor, BTF News, The British Thyroid Foundation, 9 Devonshire Place, Harrogate, North Yorkshire HG1 4AA or by email to editor@btf-thyroid.org

Please address medical queries to the Medical Enquiries Coordinator at the address above or by email to medical@btf-thyroid.org. Remember to include your membership number.

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

Medical questions, whether or not intended for publication, will normally
Could RAI have affected my fertility?

LJ writes: I had radioactive iodine treatment for my thyroid gland to treat Graves’ disease some 30 years ago.

Before treatment I had a healthy son but after treatment I could no longer fall pregnant. I went through seven years of infertility treatment and was told there was a problem with my eggs as they developed.

I have read in certain studies that they do not now regard this treatment as children bearing women. I have always blamed the treatment for not having any more children and find it very frustrating when I also read that they seem to think that this does not affect a woman’s fertility. My mum is 54-year-old with one son of 32 but would love to be contacted to find out if my fears are justifiable.

Our medical adviser replies: There is no evidence that radioactive iodine therapy for hyperthyroidism affects fertility so the reason for your difficulties with conception must not have been from the radioactive iodine treatment.

Can hypothyroidism affect male fertility?

AS writes: I was just viewing your website and noticed that your pregnancy ‘campaign’ does not offer any information for men suffering thyroid disorders. It only offers advice for women. Is this because having a thyroid disorder does not affect men as sperm count etc? As a male in my mid-50s who has been diagnosed with hypothyroidism I would greatly appreciate any information you have.

Our medical adviser replies: Hypothyroidism is an under-active thyroid. In any hormone system, both male and female, the thyroid plays an important role. The male body is a man with an under-active thyroid that is not treated correctly there is an increased chance of sperm production problems. But once the thyroid issue is resolved most sperm problems will resolve too. Thus in both men and women, if the thyroid is left untreated being well-dosed with levothyroxine, there should be no significant fertility issues in the vast majority of cases.

Ginseng

PH asks: Could you please tell me if it is possible to take ginseng with an under-active thyroid? I take 100mcg of levothyroxine daily, but I am so chronically tired even thing that I could walk a boot. I’ve heard that it’s possible to mix American (white) ginseng with levothyroxine as it’s different to red - is this so?

Our medical adviser replies: We are not aware of interactions between ginseng and levothyroxine.

If choosing to take any supplement, do so with care and not in excessive amounts, after appropriate advice from your doctor or pharmacist. Avoid those that may interfere with thyroid function. For example, some calcium rich foods and supplements interfere with levothyroxine absorption, and iodine and kelp products can be dangerous.

The ups and downs of Graves’ disease

FC writes: I have Graves’ disease. I became thyrotoxic in 2008 at the age of 37 after a highly stressful and emotional time. My mum was diagnosed as having active thyroid over a year ago.

I am sure that when she hears my personal circumstances and heredity, mine kicked off too.

I started on carbimazole but then was referred to an endocrinologist. I was trying to conceive. I did sadly have a miscarriage but I then went on to have a perfectly healthy baby girl six months ago.

I was worried about my fertility given my age and thyroid problems but thankfully it has been okay. My hyperthyroidism has now been in remission for nine months (I think my pregnancy hormones redressed the balance) now all I have to do is try to test done upon my return. I am aware that something was wrong again (I am having a recurrence of my Graves’ disease) over-active thyroid during treatment cessation). This is one area where research needs to be performed in the future.

Finally, your experience highlights the fact that although we do have treatments that manage the high thyroid hormones, we do not see many patients suffering from an autoimmune process that drives the disease (rightly more than half of patients have a recurrence of their Graves’ over-active thyroid after treatment cessation). This is one area where research needs to be performed in the future.

Is surgery the safest route for a multinodular goitre?

RK asks: I have been diagnosed with multinodular goiter. I am writing to refer to the Endocrine Department. My last blood test results were TSH -0.02, T4 - 10.4. I have told that I have a normal amount of thyroxine in the body but low TSH indicating subclinical hyperthyroidism.

I will now be under hospital care and need to know whether I should have surgery or not. I am a grandma of 8, 2 adults and I have 2 children who have been removed. One is approx 12cm in size. I have been managed for many years and currently taking the following: carbimazole 10mg with levothyroxine (two drinks a day), and there are no known side effects and other problems. However, in some people, hyperthyroidism combined with excessive alcohol intake can increase the risk of certain brain disorders, and excessive alcohol intake can impair liver function, negatively affecting central nervous system functions and medicines from the body and lead to side effects and other problems.

Should levothyroxine be lowered without a blood test?

AW asks: My mother-in-law was diagnosed with hyperthyroidism about 25 years ago. She has been on 75mcg per day ever since her levels were sorted. Her last prescription, however, is 25mcg and 50mcg on alternate days, a 50% reduction in dosage, yet she has had no blood tests prior to the dosage change.

She is 86 next birthday and has recently lost her husband of 66 years. This alone will affect her physically and psychologically, but she has gone off the scale and the family believe the hyperthyroidism is at the root of the problem. I am a qualified nurse, but did not have a blood pressure monitor with her, did not take bloods there and then but has made arrangements for nurse to go and take blood.

Is this the normal way GPs behave with elderly patients? I would love to be contacted to find out if my fears are justified.

Our medical adviser replies: It is common for older people to have a smaller levothyroxine dose, and in certain circumstances, for instance if angina or atrial fibrillation develops, levothyroxine dose adjustment would be warranted without testing the blood thyroid function measures.

In most circumstances, though, it would be usual practice for the levothyroxine dosage to be maintained. It might be necessary to test the dose in the future, particularly if so the dose is being changed significantly.

Should my hypothyroid son give up alcohol?

DM asks: My son has been diagnosed with an over-active thyroid. He drives for a living. Can you please advise if this condition increases the absorption rate of alcohol into the bloodstream or urine? I would like to know if my son should cease drinking alcohol.

Our medical adviser replies: As far as we are aware there is no conclusive clinical evidence of an interaction between thyroid hyperfunction and moderate alcohol intake to date and there are no known interactions between moderate alcohol intake and the antithyroid drug carbimazole.

The effect of hyperthyroidism on moderate alcohol uptake and metabolism is inconclusive. However, in some people, hyperthyroidism combined with excessive alcohol intake may increase the risk of certain brain disorders, and excessive alcohol intake can impair liver function, negatively affecting central nervous system functions and medicines from the body and lead to side effects and other problems.
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Continued from page 13
prescribed lovastatin (50mg daily). I have been taking this medicine ever since and my recent blood tests show that my thyroid level is returning to a normal range. Despite this, I am still gaining weight. Before this problem started I weighed 55kg and I have put on nearly two stone. I am suffering from chronic fatigue and my weight increase is mostly around my back which is making my back problem even worse. I also have cellulite.

I have been trying to lose weight ever since but nothing is really working. I am not eating much and I did not gain weight about how she succeeded in losing weight.

First ever Thyroid Eye Disease Day a huge success

The BTF recently helped to organise a special day in London which focused exclusively on thyroid eye disease and how patients can help shape research priorities for the condition.

Alex Dedman writes: as many as 128 participants gathered together at Centre Point Tower in November to learn about the current status of research in thyroid eye disease (TED), and to exchange ideas on how researchers, patients, and other supporters can work together.

Attendees included patients and their families, doctors, healthcare workers, researchers, charities and anyone else with a professional or personal investment in TED.

The event was a joint venture between the BTF and Moorfields Eye Charity Thyroid Eye Disease Charitable Trust. Fight for Sight, and the Royal College of Ophthalmologists.

This event was principally provided by Moorfields Eye Hospital NHS Foundation Trust and the Institute of Ophthalmology at University College London.

The day kicked off with the first morning session devoted to ‘meeting the researchers’ who work on thyroid eye disease. Mr Daniel Ezra, a consultant from Moorfields Eye Hospital who played a principal role in organising this event chaired this session. Eminent clinicians and researchers gave valuable insight into their patients and how their current research trends in TED — a woefully underfunded condition.

Next a panel of patients talked about their own personal experiences of TED disease. The patients’ incredibly moving stories, along with other stories from the members of the audience, really highlighted the struggles faced by patients living with eye disease.

A major theme during this session was that along with the distressing physical symptoms of the condition, there is often also a huge psychological impact for the patient. There seemed to be a consensus amongst patients that the importance of the physical and psychological cost can often be overlooked or underestimated by doctors and researchers studying the disease, as well as family and carers of the patient - and even the patient themselves.

Throughout the day patients expressed the importance of events such as this as a way of coping with the condition. Many said the support they gained from being with others who had experienced similar problems and having to explain was hugely valuable to them.

The afternoon sessions were devoted to identifying priority research areas for TED, and identifying ways patients can get involved and work with doctors and researchers to help develop and influence research agendas. This part of the day saw all participants really get stuck into the issues surrounding research into TED, with some lively debate and great exchange of ideas between the different groups.

The overriding message to come out of the day was that patients can and indeed need to have a real involvement in steering the direction of research into their condition. It was explained over and over again that doctors and researchers have found the views of patients invaluable when considering the research agenda for TED.

If patients, doctors, charities and other groups all work together then TED research will benefit hugely and a real difference can be made. Hopefully there will be many more successful activities of this nature to come.

Ou r medical advisor replies: Weight gain is often a side effect of thyropropranolol, which is one of the mainstays of modern treatment for hyperthyroidism. Before trying to lose weight be sure that your thyroid function has been normalised and that you feel well. Only then can you be sure you will have the same potential to be successful with your weight loss goals as anybody else could.

I would like to ask if you could suggest anything that can help me to lose weight as increased weight is making me less mobile and affecting everything.

People on levotyroxine will have no additional risk of gaining weight as the normal population provided their TSH is in the lower half of the reference range. A Quick Guide and leaflet on Thyroid Function Tests and reference ranges can be found on our website www.btf-thyroid.org/.

To ensure you remain as healthy as possible it is important to eat the right variety of foods and to make sure you are having enough calcium and vitamin D. To lose weight you have to eat fewer calories than you need. The more you eat, the more you will put on.

Our medical advisor replies: It is important to eat the right variety of foods to prevent you from gaining weight than the average person and it is important to adjust your weight loss goals as anybody else could.

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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.

<table>
<thead>
<tr>
<th>City</th>
<th>Telephone Number</th>
<th>Name</th>
</tr>
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<tbody>
<tr>
<td>Birmingham</td>
<td>0121 6287435</td>
<td>Janet PC &amp; CS, RIC, PH</td>
</tr>
<tr>
<td>Bolton</td>
<td>01204 853557</td>
<td>Carol PC, CS, RIC</td>
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<tr>
<td>Cambridge</td>
<td>01223 290263</td>
<td>Mary O, R, U</td>
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<tr>
<td>Coventry</td>
<td>02476 711577</td>
<td>Colin O, R, U</td>
</tr>
<tr>
<td>Edinburgh</td>
<td>0131 6647223</td>
<td>Margaret PC</td>
</tr>
</tbody>
</table>

BTF TELEPHONE 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>Name</th>
<th>Telephone Number</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dave</td>
<td>07939 236313</td>
<td>Sheryl (U) <a href="mailto:thyroid.wales@yahoo.co.uk">thyroid.wales@yahoo.co.uk</a></td>
</tr>
<tr>
<td>Jackie</td>
<td>01344 621836</td>
<td>Richard (U)</td>
</tr>
<tr>
<td>Sue</td>
<td>07784 766931</td>
<td>Denise (O, R, U)</td>
</tr>
<tr>
<td>Gay</td>
<td>020 8753 9966</td>
<td>Olivia (O, R, U)</td>
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<tr>
<td>Nia</td>
<td>01942 819195</td>
<td>Lucy (GR, RU)</td>
</tr>
<tr>
<td>Karen</td>
<td>01628 529212</td>
<td>Jane (GR, R, TED, O, U)</td>
</tr>
<tr>
<td>Wilma</td>
<td>01592 754688</td>
<td>Peter (TED, GR)</td>
</tr>
<tr>
<td>Angela</td>
<td>01943 873427</td>
<td>Penny (Ch)</td>
</tr>
</tbody>
</table>

BTF PARTNER ORGANISATIONS

- **AMEND** – Information on medullary thyroid cancer. Contact: Jo Grey 01892 516076 email: info@amend.org.uk website: http://www.amend.org.uk
- **Cancer52** – is the first registered charity in the UK dedicated solely to the support of people affected by thyroid cancer and is an organisation providing information and support about all types of parathyroid disorders. Contact: Liz Glenister 01943 873427 email: liz@hpth.org.uk website: http://www.hpth.org.uk
- **HPTH Helplines** 01342 316315 (South) and 01623 750330 (North)
- **Hypoparathyroidism (HPTH) UK** – an organisation providing information and support about all types of parathyroid disorders. Contact: Liz Glenister email: liz@hpth.org.uk website: http://www.hpth.org.uk
- **Lorraine Williams@btf-thyroid.org**
- **TEDct**, PO Box 1928, Bristol BS37 0AX. 0844 8008133 email: ted@tedct.co.uk website: http://www.tedct.co.uk
- **Thyroid Support Wales**
  - Contact: Kate Farrell 01207 546469 email: enquiries@thyroid.org website: http://www.thyroid.org.uk
  - **Butterfly Thyroid Cancer Trust** – the first registered charity in the UK dedicated solely to the support of people affected by thyroid cancer and is available to patients nationwide. Contact: Kate Farrell 01207 546469 email: enquiries@butfly.org website: http://www.butfly.org.uk
  - **Cancer52** – an alliance of organisations working to improve outcomes for patients affected by thyroid cancer and Graves’ Disease (TSH deficiency). Contact: UK 0844 8008133 email: ted@tedct.co.uk website: http://www.tedct.co.uk
  - **British Thyroid Association website**: http://www.british-thyroid-association.org
  - **British Association of Endocrine and Thyroid Surgeons website**: http://www.bates.org.uk
  - **Sense about Science website**: http://www.senseaboutscience.org.uk

BRITISH THYROID FOUNDATION DETAILS

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    - **Sense about Science website**: 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 707070 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’. Tel: 01423 709707 or 01423 709448 website: http://www.btf-thyroid.org. Office enquiry line open: Mon to Thurs, 10am - 2pm.
- Letters and articles should be sent in to Liz Clegg; e.clegg@btf-thyroid.org to arrive by 25 March 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

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<td>Overseas Outside Europe</td>
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</tr>
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Concession: unwaged, senior citizen, under-18s and students in full-time education. Please help us by ensuring that you pay the correct subscription.