COMMUNICATING THE PATIENT PERSPECTIVE - BTF ENGAGES WITH PHYSICIANS AND NURSES

In the autumn, BTF staff and volunteers travelled to meetings and conferences in Edinburgh, Harrogate, Stratford, Birmingham and London to raise awareness and to communicate the patient perspective in meetings with physicians and nurses.

Edinburgh

BTF Director Janis Hickey spoke about the importance of listening to patients during a session on thyroid disease at a symposium on ‘Diabetes and Endocrinology: Learning From Other Specialists’. The symposium took place in the hallowed halls of the Royal College of Physicians of Edinburgh on 7 October. The thyroid session was chaired by Dr Mark Strachan, Consultant Physician in the Metabolic Unit of Western General Hospital, Edinburgh.

Janis named her talk ‘The Happy Thyroid Consultation’ and said that the main purpose of her talk was ‘to represent patients and what they have told us about their thyroid disorders and about their relationship with their doctors, and to make a few suggestions’.

She emphasised that the BTF has worked closely with medical professionals from the beginning. BTF collaborates with the British Thyroid Association (BTA), the British Association of Endocrine and Thyroid Surgeons (BAETS), the Society for Endocrinology endocrine nurses group, and several other patient organisations.

After outlining the structure and the activities of BTF, Janis went on to describe the many contacts BTF has had with patients over the past 20 years. ‘From telephone calls and letters at BTF HQ, from our local groups and telephone coordinators who let us know what patients are concerned about, and from feedback from our members panel. And we have also conducted various surveys.

‘There are a lot of us out there with thyroid disorders, and I think it’s fair to say the majority of us are fine and happy. As one woman put in a letter, “thank goodness for my little white pill”. Many people have told us they have a good relationship with their doctors and recognise there are worse things in life than a thyroid disorder. But others tell us it is the worst thing that has ever happened to them.

‘A major challenge is to help the hypothyroid patients who are angry and desperate because they feel they are not being listened to. Their concerns are often fuelled by the media, and sometimes patients are driven to go on the internet, find dodgy websites, and get into self-diagnosis and treatment.’

‘The patients who contact us have a wide range of needs, from those who have just been diagnosed and want to know more, to those who ask “Why me? What next?” And those with specific queries that they don’t want to put to a doctor, such as “I ran a marathon two years ago, can I still do that?” and “Can I eat the same food?”

‘And then there are people who come across a magazine article, see a programme on TV or hear a discussion on the radio, who see the list of symptoms and believe that they too have a thyroid disorder. If they call us we advise them to see their doctor and to get a blood test. Some, though, have already seen their doctor and have been told their test is normal, but are still convinced they have a thyroid disorder. They may call us back and phone around our telephone support volunteers on several occasions and of course it is challenging to help them.

‘Others have had a thyroid condition diagnosed many years ago and still find it difficult to deal with.

‘And occasionally we have had calls from the suicidal.’

Janis then summarised the common concerns of patients: ‘Hair loss distresses a lot of people, and other symptoms that people find particularly distressing are weight gain, concentration difficulties, brain fog, and eye changes.

‘Other, important, concerns are about communicating with doctors, getting a blood test, or getting a repeat test, and understanding what the doctor is saying.

Continued on page 2
‘Doctors often say things like “you’re within the reference range” meaning “you’re normal” without explaining what the reference range is and whether there might be scope for manoeuvre. Many patients tell us that they want to know the actual numbers and to get an interpretation from the doctor not the receptionist.

‘And then there are questions from people who want to stay on the same brand of levothyroxine rather than keep changing (we get divided advice from the professionals here, some saying there is no difference between brands, while others say there could be). And from people who have heard about Armour and T3 and wonder whether these may help them feel better. And there are some people who have read that eating kelp will kick-start a sluggish thyroid.

‘We have heard from patients who, despite being on a stable dose, are still given prescriptions for only 28 days, and we have made several representations to the Department of Health and said that we think that they should receive prescriptions for a minimum of three months as is the case in many other countries.

‘We have also heard from patients who find it difficult to split tablets, or to take different strengths on alternating days, and we have told the manufacturers that we would like to see more strengths.

‘Patients also tell us that they don’t always get reminders to make annual appointments, that they aren’t told - or learn very much later - how medicines and food can affect thyroxine replacement.

‘There are different medical opinions and lack of consensus on some issues, so people wonder who to listen to. For example, sometimes an endocrinologist has prescribed levothyroxine at one level and the GP has changed it.’

Janis also used the opportunity to explain the BTF’s current campaigns including raising awareness of thyroid disorders in pregnancy. (For more information about the BTF projects see the updates on page 6 of this newsletter, or go to the website www.btf-thyroid.org.)

Her main take-home messages were: ‘A lot of these concerns come from people with an under-active thyroid. What patients want is improved communication and explanations, to know what is happening, and why; to be told about tests, treatments, and care options; to have their concerns taken seriously, to be heard, to be treated as individuals, and - of course - to feel better!

‘Here is some food for thought. If a patient says “I don’t feel right” is it enough to say “you can’t be ill because your tests say you’re normal?” Is the patient wrong? Or do we really know everything there is to know about thyroid disorders?’

She recommended that doctors avoid jargon, especially when talking with the newly diagnosed, that they explain the ‘reference range’ of blood tests and consider if there is room for manoeuvre, to leave the door open for questions, and give access to reliable sources of help.

Harrogate

In Harrogate, BTF had an exhibition stand at the fourth Royal College of General Practitioners (RCGP) Annual Primary Care Conference. The Conference theme was ‘Sustainable Primary Care: Growing Healthy Partnerships’.

Donna Reed and Cheryl McMullan at the BTF booth at the RCGP conference, Harrogate

The BTF representatives at the conference were Cheryl McMullan, Donna Reed, and Jennifer Linley. The emphasis on the BTF stand was on raising awareness among GPs of the risks and recommended treatment for thyroid problems in pregnancy. GPs were very interested in the information on display and Donna and Cheryl had to keep returning to the office for further supplies.

BTF volunteer Vivienne Rivas presented the thyroid patient’s perspective at a workshop chaired by Sile Lane of Sense About Science during the RCGP conference with the title ‘I’ve got nothing to lose by trying it’.

Vivienne was diagnosed with an under-active thyroid five years ago. She spoke about the reasons why patients with chronic illnesses sometimes seek out alternative remedies.

She described how some patients report feeling unwell, depressed, isolated from family and friends, trapped, powerless and unheard, even after starting medication. As she said, ‘the test results outrank your symptoms every time’.

The common responses are:

‘The blood tests show you’re normal; ‘Come back in 6-12 months if you still feel the same;

‘You’re within the reference range;

‘Your other condition has nothing to do with it;

‘The symptoms must be something else; and

‘This is the only treatment option - (we know it’s not perfect).’

Vivienne herself had not sought out alternative therapies, she said, ‘because basically I am a rationalist who believes science knows best, even when it gets it wrong’. But she acknowledged that, with the mass of information and remedies available today at the click of a mouse, most of it unknown 30 years ago, patients are ‘surrounded and indeed bombarded with this stuff, even if we don’t look very hard’.

Vivienne made a plea that GPs, as the first port of call for people with chronic conditions, can play an important part in ensuring that people do not squander their hopes and their money on unproven remedies, and to be more discriminating in their choices, ‘by framing appropriate responses to those people who keep turning up in the surgery who are not desperately sick, but who never feel well’.

She recommended that GPs should:

‘Show care and concern for our overall well-being, not just our biochemistry;

‘Communicate better by hearing what we say about our symptoms and try actively to alleviate them;

‘Instil confidence by reviewing and explaining all the treatment options;

‘Help us coordinate the management of our sometimes multiple conditions;

‘Acknowledge that current treatments don’t necessarily make us feel better, even if they control the disease;

‘Encourage us to understand that research may bring better solutions in the future; and

‘Help us to evaluate new and alternative treatments.’

These measures ‘would help patients to regain control over their lives so they can continue to function comfortably and successfully, and so give doctors more time to deal with other, and perhaps more pressing, cases’ she said.
**‘I’ve got nothing to lose by trying it’**

*I’ve got nothing to lose by trying it* is the title of a booklet published by Sense About Science together with the Multiple Sclerosis Society, Motor Neurone Disease Association, Alzheimer’s Society and Parkinson’s Disease Society. It aims to explain how to tell the beneficial from the bogus in the face of the miracle cure stories, new wonder-drugs and breakthrough therapies that are increasingly promoted. See www.senseaboutscience.org.uk for further details.

---

**Stratford**

The Society for Endocrinology’s Endocrine Nurse Update was held in Stratford-Upon-Avon on 27-28 September. BTF Director Janis Hickey and BTF Project Facilitator Donna Reed attended the meeting. They write:

This was the inaugural meeting of the newly designed Endocrine Nurse Update organised by Nikki Kieffer, Endocrinology Practice Nurse, who is also a member of the BTF’s Thyroid in Pregnancy Project, and holder of the BTF 2010 Nurse Award.

---

**Birmingham**

The British Association of Endocrine and Thyroid Surgeons (BAETS) held its annual meeting in Birmingham on 21-22 October 2010

Janet Prentice, BTF local coordinator for Birmingham, represented the BTF at this event.

---

Janet writes: ‘There was lots of interest at the stand. Some of the posters, newsletters, quick guides, Christmas card order forms and most of the thyroid cancer booklets were taken.

‘A delegate from Belgium commended the work done by BTF and was even more impressed when he heard it was a patient-founded and led non-profit charity.’

---

**London**

The first National Rarer Cancer Conference took place at Chelsea Football Club, London on 28 October.

Representatives of patient organisations and networks around the country took part and Carole Ingham and Judith Taylor of the BTF Thyroid Cancer Project Group were there to represent BTF and to display BTF materials at the exhibition.

---

The conference was well attended, and although the participants would not have filled the stadium (the meeting took place in a conference suite at the club) the mood was upbeat and the room was full of engaged representatives who came ready to share their experiences and keen to ensure that health services listen to representative voices of rarer cancers in making their plans.

The aim of the conference was to help improve the patient journey for people with a rare cancer. As Ray Murphy, Chair of the National Cancer Partnership Forum, pointed out, over half of cancer deaths are from the rare or less-common cancers.

**Professor Sir Mike Richards,** National Director of the National Cancer Action Team, described the progress to date with the refreshment of the Cancer Reform Strategy (the BTF provided input to the refresh process via Cancer 52) and asked delegates what they would like to see in the strategy about ‘rarer cancers’.

The conference also included presentations from Andrew Wilson, Chief Executive of the Rarer Cancers Foundation, and Simon Davies, Executive Director of Cancer 52, about their respective organisations.

---

The core of the conference, however, was a series of round-table discussions about developing a national rarer cancer pathway. Delegates gave their views on what they would like to see the pathways include in four round-table discussions on tests/investigations, diagnosis, treatment, and post treatment.

Paula Lloyd, Associate Director of the National Cancer Action Team, summarised the common issues from the round-table discussions and outlined the next steps which will include the identification of actions at network and national level.

The BTF stand was well-attended and several people took away information about the BTF thyroid cancer booklet.

---

**NEWS ABOUT BTF**

---

**A CHRISTMAS WISH**

BTF’s Christmas wish is to see our membership grow in 2011. Can you help us to achieve this? If every member could introduce just one new person to the BTF next year this would be the best Christmas present ever!

---

**We apologise ....**

Owing to a mailing error some members notified us that they didn’t receive their newsletters. Our mailing house, Cambertown Ltd, has kindly rectified the situation.

---

**New BTF website attracts many more visitors**

Volunteer Claire Skafie, who is the BTF Webmaster, gave a presentation to BTF Trustees at the Board of Trustees meeting in October.

Continued on page 4
Welcome to ...

Greg Sadler MD, FRCS, who has joined the BTF Board of Trustees.

Greg Sadler is Consultant Endocrine Surgeon at the John Radcliffe Hospital, Oxford, UK.

Procedures include parathyroid, thyroid and adrenal surgery. He also has an interest in hernia surgery and runs the Oxford Hernia Clinic. He sees both NHS and privately referred patients in Oxford and at a private clinic in Harley Street, London.

He is currently Secretary of the British Association of Endocrine and Thyroid Surgeons (BAETS). He lectures nationally and internationally, publishes regularly in peer-reviewed surgical journals, and has written many book chapters on aspects of endocrine surgery.

Greg Sadler, who has over 18 years’ extensive experience in endocrine surgery, qualified in 1982 from the University Hospital of Wales and gained a wide base of experience in general surgery and plastic surgery before moving to Oxford as Senior Registrar in General & Endocrine Surgery in 1993. He also trained with the internationally renowned surgeon Professor Orlo H Clark at Mount Zion Hospital, San Francisco.

Over the past six years he has pioneered the development and use of the Harmonic Scalpel in thyroid surgery. He was the first UK surgeon to use the technology for thyroid surgery and has now performed or supervised over 1,000 procedures with the Harmonic Scalpel. For the past five years he has organised an international course to teach other thyroid surgeons in its use.

Thanks to ...

Angela Ward, who strengthened the team of volunteers in the BTF office over the summer dealing with medical queries.

Farewell to....

Dr Grace Gibson and Ms Alison Wagborn, who have stepped down from the BTF Board of Trustees. Our thanks to them for their support.

Obituary: Claire Rayner OBE

We were sorry to learn of the death of our Patron Claire Rayner OBE, who died on 12 October 2010.

Claire chaired a health event in Harrogate in 1994 and BTF Director Janis Hickey approached her at the event to ask if she would become a BTF Patron. Claire had been treated for a thyroid disorder when she was young and immediately said yes.

Claire Berenice Chetwynd was born in the East End of London. The family emigrated to Canada in 1945. She made no secret of the fact that she had a dreadful childhood, which reached a low point when her parents put her in a psychiatric hospital in Canada for fifteen months. Eventually she was diagnosed with Graves’ disease and had a thyroidectomy.

Back in England, Claire trained as a nurse and worked as a nursing sister in the 1950s, specialising in paediatrics and midwifery. Her marriage and the birth of her first child in 1960 ended her nursing career and she turned to writing. She wrote more than 100 books, both fiction and non-fiction, but was perhaps best known for her role as an agony aunt for several magazines and newspapers and her appearances on radio and television, and later as an activist on health issues. She was famous for opening the windows on previously taboo subjects and for her blunt but empathic approach.

As well as the British Thyroid Foundation, Claire was a Patron of many other organisations including the Terrence Higgins Trust, the Medical Foundation for the Care of Victims of Torture, Pain Concern, and the Right to Care Campaign; she was also President of the Patients Association, a lobby group that aims to improve patients’ experience of
health care; and a former President of Gingerbread, the National Association of Bereavement Counsellors, and the British Humanist Association. She was given an OBE in 1996 for services to women’s issues and health issues.

Of the BTF she wrote: ‘[O]ver fifty years ago I became ill with acute thyrotoxicosis - Graves’ disease … suffice it to say that I eventually was treated successfully with a thyroidectomy which, undoubtedly, saved my twenty-year-old life. With that history, how could I not accept an invitation to become a Patron of the British Thyroid Foundation? If they can help other young people (or indeed people of any age!) to cope with this unpleasant condition - and it’s just as unpleasant if you have a shortage of thyroid hormone rather than an excess as I did - then I want to do what little I can to help. I hope other people will see them as well worthy of support as I do’.

Claire is survived by her husband Des and their two daughters.

Her much-quoted last words were: ‘Tell David Cameron that if he screws up my beloved NHS I’ll come back and bloody haunt him’.

Sources: Various obituaries including The Daily Telegraph, The Guardian, Wikipedia.

The meeting attracted about 40 participants and was hosted by Dr R Ajjan, Consultant Endocrinologist, and Mr B Chang, Consultant Ophthalmologist, who were joined by colleagues who presented talks.

Dr Ajjan gave presentations on thyroid disorders and on the medical management of thyroid disease; Mr El-Hindy explained thyroid eye disease and spoke about surgical aspects of thyroid eye disease; Ms L Pankethman talked about double vision, and BTF Director Janis Hickey gave a talk about future aspects of thyroid eye disease, in which she described the BTF/TEDct project. A powerful presentation was made by a thyroid eye disease patient who described the impact of temporary sight loss on his life, and spoke about his recovery.

Dr Ajjan made the following points about how thyroid eye disease is managed at St James’s Hospital.

- All patients are seen in a joint clinic.
- Guidelines have been prepared to indicate when to refer patients urgently for surgery, e.g. rapid deterioration in vision, sudden proptosis, corneal opacity and failure of eye closure.
- Management is assigned according to the severity of thyroid eye disease.
- In mild disease, artificial tears, diuretics, and/or anti-inflammatories are prescribed.
- If more intervention is needed topical steroids are used.
- If even more intervention is required oral steroids or intravenous steroids can be given, but logistically the latter is more difficult as patients require day care in hospital.
- Radiotherapy is used where more intervention is required – this takes six weeks to two years and is more effective when combined with steroids.
- Radiotherapy should not be used if the patient is under 35, diabetic with eye complications or hypertensive.
- Radiotherapy can be given in divided doses but cannot be repeated.
- Surgery is used in an emergency or at the end of treatment when the disease has dissipated.
- Drugs - the immune system is targeted with steroids, cyclosporine, azathioprine (limited efficacy), methotrexate, rituximab, or etanercept in last resort cases.
- It was pointed out that it was important to stop smoking, and to remain euthyroid (i.e. maintain thyroid levels within the reference range) - measures used were a ‘block and replace’ regimen, using levothyroxine and carbimazole.

In summing up, Dr Ajjan pointed out the following helpful reminder:

T = tobacco abstinence
E = euthyroidism,
A = artificial tears
R = refer

We are grateful to Dr Ajjan and Mr Chang for helping to organise the event and for providing the facilities.

Thanks to Liz Baister of TEDct for providing the information this report is based on.

Sense About Science wins at Medical Journalist Awards

Congratulations to Sense About Science (SAS) for being chosen as Health Charity of the Year 2010 at the Medical Journalists’ Association awards in July. The award, presented at the awards ceremony at the Royal Society of Medicine, was given to SAS for its work in campaigning for the reform of England’s libel laws.

Sense About Science is a partner organisation of the BTF. The BTF and the British Thyroid Association (BTA) are among the organisations that have signed in support of libel law reform, see: http://www.libelreform.org/who-supports-us.

BTF PROJECT UPDATES

A round-up of what our project teams have been up to in the last three months.

Thyroid Eye Disease

Janis Hickey writes: We held a telephone conference in October where medical and patient representatives of professional organisations with an interest in thyroid eye disease discussed ways of improving treatment and care for people with thyroid eye disease in the UK.

We are currently seeking publication of our article about decompressive surgery in the UK, and will be seeking support for our application for NICE and SIGN guidelines to be produced.

We are also preparing a text to distribute to health professionals, e.g.,
ophthalmologists, endocrinologists and medical professionals who administer radioactive iodine treatment for Graves’ disease, in order to raise awareness of the symptoms of thyroid eye disease and the importance of maintaining euthyroidism (and, in particular, avoiding hypothyroidism).

**Thyroid and pregnancy**

Donna Reed writes: Members of the Pregnancy Project Group met in Birmingham at the Birmingham Women’s Hospitals. Those attending were Professor John Lazarus, Dr Shiao Chan, Nikki Kieffer, Janis Hickey, and Donna Reed. Our discussion centred on reaching the GP with our Thyroid in Pregnancy campaign.

![The pregnancy project group meets in Birmingham. Left to right: Dr Shiao Chan, Nikki Kieffer, Professor John Lazarus and Donna Reed](image)

Since then, we facilitated an information booth at the Royal College of General Practitioners conference in Harrogate (see lead story) where we had a new poster and distributed our TIP (Thyroid in Pregnancy) card and information about BTF. There was also discussion about appropriate TSH/T4/T3 levels for pregnant women and how to create awareness. As a group we decided to invite a midwife and an additional GP to become a part of our project.

The September issue of *Midwives, the Magazine of The Royal College of Midwives*, published an article called ‘Too much or too little?’ written by BTF Trustee Professor John Lazarus and midwife/health visitor, Emma Louise Cuthbertson-Smith. The article discussed the issue of appropriate levels of levothyroxine for pregnant women and risks.

**Thyroid disorders in children**

Penny Root writes: The Children’s Corner seems to have been a success not only with children who are glad to know they are not alone, but also (so we have been told) with many adults who find its discussions of thyroid problems clear and comprehensible.

We have been discussing the design of a thyroid information poster for paediatric clinics. Many parents are desperate for reliable information beyond the doctor’s office but hardly know where to begin.

**Thyroid cancer**

Carole Ingham and Judith Taylor write: We are delighted to announce that Mr Greg Sadler (Endocrine Surgeon, Oxford, and BTF Trustee) and Dr Kate Newbold (Consultant Clinical Oncologist at the Royal Marsden Hospital, London) have agreed to join our project group. We hope to arrange a meeting early in the New Year.

In October, Carole and Judith both attended the National Rarer Cancer Conference (see report on page 3). In November Judith represented BTF at the National Cancer Action Team stakeholder meeting to discuss the process for submitting content to the cancer information pathways.

In the meantime we are continuing to gather information for our two projects on travel health insurance and our survey of radioactive iodine treatment rooms in the UK.
Dr Moran writes: Resistance to thyroid hormone (RTH) is a relatively rare condition, resulting in high levels of thyroid hormone, 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 overactive thyroid (e.g. palpitations) in adult life. Unfortunately, RTH is often not recognised or diagnosed by doctors and therefore not treated appropriately. In addition, little is known regarding the long-term adverse effects of living with this disorder.

Recently, it has been suggested that individuals with RTH do not use sources of energy (such as glucose, fat or protein) normally, or respond to the hormone insulin in the usual manner.

Our preliminary data also show that they have high cholesterol levels and stiff (inflexible) arteries. Together, these abnormalities are likely to result in a significantly increased risk of vascular disorders such as heart disease and strokes.

Our research study is designed to analyse the metabolism of patients with RTH, and in particular how their body uses and responds to various energy sources such as glucose, fat and protein. We will use a number of methods to investigate this, including performing blood tests and studying the body’s use of stable isotopes during the controlled administration of insulin.

A state-of-the-art type of scanning - Magnetic Resonance Spectroscopy (MRS) - will allow us to obtain unique biochemical information about fat storage in muscle and liver in a painless and non-invasive manner. In a small number of patients, a biopsy of muscle tissue will be taken to determine how the presence of the abnormal thyroid hormone receptor in muscle cells influences metabolic pathways. These findings will be correlated with those from the MRS studies.

Thus, for the first time we will be able to gain a detailed picture of the altered metabolism in RTH patients, and thereby understand how this might translate into increased cardio-metabolic risk. We anticipate this will allow better targeting of therapy (both with conventional drugs and newer agents) in this patient group, while at the same time increasing our understanding of thyroid hormone action in general, which has direct relevance to the management of patients with more common thyroid disorders (hyper- or hypothyroidism).

Details of the 2011 application procedure can be found on the BTF website: www.btf-thyroid.org

Nurse-led telephone consulting

Fiona Anthonypillai

The 2009 Evelyn Ashley Smith Nursing Award was made to Fiona Anthonypillai, Clinical Nurse Specialist, St George’s Hospital, Tooting, London, for her project entitled ‘Nurse-Led Thyroid Telephone Consulting’. Below is the final report.

Fiona writes: Patients with thyroid disease are generally referred to an endocrine clinic. Here they are seen by an endocrinologist who then decides on the course of treatment required. In most departments this involves numerous visits to the clinic for the patient, to review their condition. These visits are often time-consuming, costly and inconvenient for our patients. On many occasions, the visit may just be a matter of looking at the blood tests and increasing or decreasing the medication.

To avoid unnecessary clinic visits and reduce waiting lists for patients, a nurse-led thyroid telephone clinic was set up in 2006. Those patients who are deemed suitable for this service are referred to me by the endocrinologists.

The endocrinologists indicate when the patient is to be reviewed and what their present thyroid function blood results are. A starter pack is then sent out which includes a thyroid record booklet, appointment letter and blood test form. The letter introduces the patient to the telephone service and states when their next blood test should be taken.

The record booklet briefly explains about the thyroid gland and symptoms of hypothyroidism and hyperthyroidism. The booklet also contains a record sheet for patients to record their results and treatment and any advice given. At the back of the booklet there is a table to record their list of medication and useful information regarding thyroid medication and support groups.

The patient is then telephoned with their results, and advice is given to change their medication accordingly. This provides the patient with an opportunity to discuss their condition and any queries or concerns they may have. The patient is advised that if they wish to be seen by a doctor in clinic, this will be arranged at the earliest opportunity. Should a patient not have their blood test within a week of the appointment date, a letter is sent out to remind the patient of the blood test. A written and an electronic record is kept of the patient’s results, treatment, correspondence and review date.

At present we have more than 300 patients using this service. It is hoped that this has improved and will continue to improve the thyroid service offered to patients by St George’s Hospital NHS Trust and that other departments may develop their service in a similar way.

‘The Award has helped with the costs of producing and updating the thyroid booklet in a professional format for patients and has provided extra resources for patient support.’ says Fiona. ‘The future plan will be to audit the use of this service in order to continually optimise patient care.’

Fiona concludes: ‘I would like to thank the British Thyroid Foundation for giving me the opportunity to further enhance the service we offer to thyroid patients.’

Details of the 2011 application procedure can be found on the BTF website: www.btf-thyroid.org
DONATIONS

Many thanks for your generous donations. We are grateful for them all, including those donated by members at the time of joining BTF or at renewal time, which are too many to list here.

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, 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 it in BTF News and the BTF website.

Congratulations and thanks to our brilliant fundraisers

Judith Davis who ran the Great North Run dressed as a bottle of beer and has raised £734 to date (her target was £300). Judith says:

‘I’m pleased to say we all survived the Great North Run, and as you can see from the photos, the girls wore their British Thyroid Foundation vests, but as I was dressed as a giant beer bottle, I couldn’t get my vest over the top. I have to say I was proud to be running for your charity, and for two very good friends who have both suffered the stress of having thyroid cancer’.

Mrs Tilly Kelly who raised £386.25 at a line dance party in her local school hall to celebrate her 60th birthday. Over 100 people attended. Tilly has her own line dance class called ‘Red Hot Tilly Steppers’ (see photo) and says ‘It’s a brilliant pastime which keeps you fit in mind and body’.

Ian Cousins from the Poulton-le-Fylde golf club for a donation of £100 made through Dave Worrall. Ian made some wonderful donations during Dave’s year as Captain, in which Dave named BTF as his chosen charity. (See lead story in BTF News 73, summer 2010.)

We would also like to thank the following

Mark Vanderpump and Michael Tunbridge for a further donation arising from the royalties from their book Thyroid Disease: the Facts - £73.88 for the period October 2009 to March 2010.

Mrs S Miller for a £220 donation in lieu of presents for her Golden Wedding.

Elaine Viles for the £606 donated in memory of her husband Stephen Mark Viles.

Mr M Poole for the kind donation of £25 in memory of his mother Mrs Kathleen Poole.

Thank you to Lloyds Bank for donating £500, as part of its match-funding scheme, which it sent to BTF following the recent fundraising endeavours of Michael Smout who is halfway towards his goal of climbing all the Munros in Scotland (see BTF News 74).
IS THERE A LINK BETWEEN DENTAL X-RAYS AND THYROID CANCER?

A collaborative study by scientists from Brighton, Cambridge and Kuwait on a possible link between exposure to dental x-rays and thyroid cancer was widely reported in the press earlier this year and has stimulated queries by patients and the public. The authors concluded that the risk of thyroid cancer increased with the number of dental x-rays taken. They point out however that the results should be treated with caution and that further studies are needed.

Representatives of the dental profession have stated in the press recently that the number of x-rays being taken in dental practice in the UK has greatly reduced in recent years and that the amount of radiation from modern equipment is extremely low. Our Medical Editor Dr Petros Perros recommends against changing our behaviour in terms of visiting our dentist and says it would seem unjustified not to allow dental x-rays if the dentist recommends it.

The research team have called for further studies using dental x-ray records.

The research was funded by the Kuwait Foundation for the Advancement of Sciences (KFAS) and was administered by the Kuwait University Research Grant Administration.

We asked Dr Petros Perros, Clinical Endocrinologist at Newcastle Upon Tyne Hospitals Foundation Trust and Medical Editor, BTF News, to comment. Dr Perros writes:

‘This study was performed in Kuwait. Patients with a known diagnosis of thyroid cancer were interviewed and asked to provide an estimate of exposure to dental x-rays. A matched control population went through the same process. Exposure to dental x-rays was found to be significantly greater in patients with a history of thyroid cancer.

‘What should we make of this? It is already well known that high doses of radiation (e.g. radiotherapy to the neck, or exposure after a nuclear accident) definitely increase the risk of thyroid cancer, especially if the exposure takes place in childhood. Dental x-rays are much lower energy and considered to be safe. There is already a literature on the link between dental x-rays and risk of thyroid cancer, but the data are conflicting. Some studies show an association, others do not.

‘One difficulty with the Kuwaiti study and other similar ones is that it relied on the subjects’ recollection for the dental x-ray data. This is subject to bias. A second difficulty from such studies is that even if there is a link, it is not necessarily a cause and effect relationship. For instance, people who are more health conscious

The researchers studied 313 thyroid cancer patients in Kuwait where dental treatment is free and where the incidence of thyroid cancer is relatively high compared to Britain. They point out that this is the largest case-control study on the subject to date but explain that the results should be treated with caution because the data were necessarily based on self-reporting by the participants. Comprehensive historical dental x-ray records were not available from the clinics.

They said the results provide good evidence to warrant more research in settings where historical dental x-ray records are available and where doses of radiation can be estimated.

Dr Memon said these findings were consistent with previous reports of increased risk of thyroid cancer in dentists, dental assistants, and x-ray workers which suggest that multiple low-dose exposures in adults may also be important. He said dental x-rays have also been associated with an increased risk of brain and salivary gland tumours.

He said: ‘The public health and clinical implications of these findings are particularly relevant in the light of increases in the incidence of thyroid cancer in many countries over the past 30 years.

‘It is important that our study is repeated with information from dental records including frequency of x-rays, age and dose at exposure. If the results are confirmed then the use of x-rays as a necessary part of evaluation for new patients, and routine periodic dental radiography (at 6–12 months interval), particularly for children and adolescents, will need to be reconsidered, as will a greater use of lead collar protection.’

He added: ‘Our study highlights the concern that like chest (or other upper-body) x-rays, dental x-rays should be prescribed when the patient has a specific clinical need, and not as part of routine check-up or when registering with a dentist.’

He concluded: ‘The notion that low-dose radiation exposure through dental radiography is absolutely safe needs to be investigated further, as although the individual risk, particularly with modern equipment is likely to be very low, the proportion of the population exposed is high.’

Continued on page 10
may be visiting dentists more often and may also be more likely to have investigations for thyroid cancer.

‘Should we change what we do in the light of this study? There is a need for the scientific community to investigate the relationship between thyroid cancer and dental x-rays more rigorously, so that we have a definitive answer. In the UK the use of dental x-rays has declined greatly in recent years and the dose of radiation emitted from modern dental x-ray machines is very low, yet the incidence of thyroid cancer in the UK is increasing. This would suggest that the role of dental x-rays in the evolution of thyroid cancer cannot be a major factor, if a factor at all. Dental checks are essential for oral hygiene and poor dental health is associated with significant health risks, including for instance heart disease.

‘Dental practice in the UK abides by a high standard of professionalism, so whenever dental x-rays are recommended there is a good reason why they should be performed.

‘Changing our behaviour in terms of visiting our dentist, and not allowing dental x-rays to be taken if the dentist recommends it, would seem unjustified.’

In the Daily Mail of 8 June 2010 Dr Nigel Carter, Chief Executive of the British Dental Health Foundation, is quoted as saying:

‘The number of x-rays being taken in dental practice in the UK has greatly reduced in recent years and the dosages from modern equipment are extremely low.

‘Dental x-rays have a valuable role in the diagnosis of dental disease.’

In the same article Dr Martin Fallowfield, a Peterborough dentist and British Dental Association spokesman, comments that the number of x-rays he takes has changed over the years and that he takes fewer now than when he started practicing. ‘The technology that we use to take x-rays has also changed, and lower doses of radiation are used’ he adds.

‘The need for x-rays won’t go away though, and dentists are required to undertake training to ensure they are up to date with the latest techniques in deciding when and how to take x-rays.

‘That keeps this hugely valuable tool safe and at our disposal in caring for our patients’ he concludes.

References

Brighton and Sussex Medical Schools Press Release: Dental x-ray link to thyroid cancer. Downloaded 26 Oct 2010. http://www.bsms.ac.uk/school-and-

THYROID SCREENING IN EARLY PREGNANCY

Preliminary results of the CATS study

Endocrinologists have been debating for years whether women should be screened for thyroid function in early pregnancy. One major study published ten years ago showed that hypothyroidism may also affect the intelligence quotient (IQ) of the baby. Professor John Lazarus and colleagues at Cardiff University set out in 2002 to test whether screening women for hypothyroidism and treating them early in pregnancy improves the intellectual development of their children. The Controlled Antenatal Thyroid Screening Study (CATS) ended earlier this year and Professor Lazarus presented the preliminary findings at the International Thyroid Congress held in September in Paris.

We invited Professor Lazarus, who is a BTF Trustee and member of the BTF thyroid and pregnancy project group, to explain the findings of the study for the benefit of BTF News readers. He writes:

During the past two decades there has been an increase in our understanding of the effect of thyroid disease on pregnancy and this has led to improvements in treatment.

Thyroid dysfunction is common in pregnancy. For example, hypothyroidism may occur in up to three per cent of pregnant women.

Two questions arise. First - does an under-active thyroid in the mother affect the pregnancy and the baby? And second - how easy is it to diagnose this condition in pregnancy?

Hypothyroidism, even the mild subclinical form, may lead to obstetric problems during delivery and may also result in pre-term birth. And, according to an important retrospective study of more than 25,000 women by Dr James Haddow and colleagues of the Foundation for Blood Research in Scarbororough, Maine, USA, published in The New England Journal of Medicine in 1999, it may also affect the baby. Researchers found that women not treated for hypothyroidism during pregnancy had children whose intelligence quotient (IQ) was lower than those children from mothers with normal thyroid function.

In most women who are hypothyroid in pregnancy the diagnosis is difficult because many of the symptoms are similar to those of normal pregnancy. Only a thyroid function test can make the diagnosis. In order to prevent the reduction in IQ in children, the assumption is that it would be advisable to screen all women in early pregnancy and give levothyroxine to those with hypothyroidism.

The trial to test this assumption has just finished. In the Controlled Antenatal Thyroid Screening Study (CATS) blood samples were obtained before sixteen weeks’ gestation from 22,000 women in Cardiff and in Turin, Italy and assigned at random to a screen group and a control group. In the screen group, the samples were immediately tested for thyroid hormones. In the control group, the samples were tested after the woman had delivered.

In the screen group, about 3.5% of the women were found to be hypothyroid and these received 150mcg of levothyroxine for the remainder of their pregnancy. In the control group, the women were informed after birth if they had a thyroid problem and they then visited their GP for advice. (As this study started in 2002 when there was no thyroid screening in Europe, there was no ethical problem.)

When the children born to both groups were about three years old their IQ was measured by expert psychologists who did not know whether the mother had taken levothyroxine during pregnancy or not.

There is a degree of uncertainty about the overall trial outcome. The preliminary analysis suggests that there may be no benefit of screening for thyroid disease in pregnancy in terms of child IQ at least, because when the results of the IQ testing
are analysed on an intention-to-treat basis (i.e. without knowing whether the women took their medication as prescribed) there was no significant difference.

However, when the results are examined among the women whose blood levels showed that they had definitely taken their levothyroxine, the results change. In this sub-group, the percentage of children in the screen group with an IQ less than 85 was 9.2% compared to 15.6% in the control group - a significant difference.

Further analysis of the results of this trial is being performed.

Where does this leave us in relation to screening for thyroid dysfunction in early pregnancy? Some experts think that the evidence (obstetric, neonatal and childhood) in favour of screening is only fair or poor and that universal screening cannot therefore be recommended. Others feel that universal screening should be recommended even with the current levels of evidence.

At the moment the data argue against population-based screening and treatment for these women. This leaves the decision of whether to screen and treat up to the individual physician. The USA Endocrine Society guidelines presently argue that testing should only be done in early pregnancy if there is some significant risk factor. But other studies show that if you adopt this method, you miss a significant number (30-50%) of women who should be treated. So the debate is likely to continue for some time to come.

References


Lazarus J. SY 18. Pregnancy and thyroid diseases. Presented at: the 14th International Thyroid Congress; Sept 11-16 2010; Paris

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

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

Hypothyroidism and muscle pain

CV asks: I have had an under-active thyroid for over fifteen years since the menopause and had no idea that muscle pain was a symptom until reading the Case Study on Page 10 of BTF News 72 (spring 2010). I have had continuing and increasing muscle pain for several years in my right thigh and had assumed that it was just normal aging and that I might need a new hip in due course. The pain has never felt as if it was located right in the hip joint however and is more diffuse into the muscle itself.

My consultant said that continuing muscle symptoms in hypothyroidism is a ‘rare’ symptom. Could this be because most patients, like me, have no idea that this is something that can occur and therefore don’t mention it to their doctors? And if no one mentions it then it is not surprising that ‘no research has been done’. Is it possible to diagnose this problem accurately, is it correct that there is no treatment and how rare is it?

Our medical advisor replies: Muscle pain can be a symptom of an under-active thyroid (hypothyroidism). However, muscle pain related to hypothyroidism improves with treatment with levothyroxine and it is unusual for muscle pain to continue for several years if you have been optimally treated with levothyroxine. Muscle pain can occur due to many other causes such as medications (for example, statins), polymyalgia rheumatica, inflammation of muscles, trauma, etc. You should talk to your doctor about your symptoms and seek their help.

Drugs that affect levothyroxine absorption (1)

DD asks: My doctor put me on iron tablets last October. There were no instructions as to when to take the iron tablets (or when not to take them), so I just took them at the same time as my levothyroxine. It was only when I saw the article in the last issue (BTF News 73, summer 2010) that said the iron stopped absorption of levothyroxine, that I then started to take the iron tablets in the evening, but by then, I had been taking them for five or six months.

Your article suggests that you should also not take levothyroxine at the same time as a selection of other medications. I also take omeprazole capsules (gastro-resistant) 20mg a day. This is taken at the same time as the levothyroxine - again, I have not been told not. Is this okay? My concern is that omeprazole lines the stomach lining to stop gastric reflux - would that lining stop the absorption of levothyroxine?

Should I have regular blood tests to check the iron levels?

Our medical advisor replies: The absorption of levothyroxine can potentially be reduced by a number of different medications including iron tablets, calcium tablets and possibly tablets that reduce acid production, such as omeprazole and lansoprazole. In addition, fibre-containing foods, such as bran in breakfast cereals, can also reduce the absorption of levothyroxine, so advice is normally given to patients to take levothyroxine at least half an hour before breakfast.

It makes sense to avoid taking medications that can interfere with levothyroxine absorption at the same time as taking the levothyroxine and to take these later in the day if possible.

Most patients who take omeprazole, in my experience, have no problems with levothyroxine absorption. But if you are leaving a gap between taking your levothyroxine and other medications such as iron tablets, it would make sense to take your omeprazole at a different time of day as well.

With respect to the monitoring of your blood count and iron levels, there are no set rules for checking these regularly, and depending on the cause of the iron deficiency, the iron levels often return to normal and stay normal after a course of iron treatment. If you are concerned about your iron levels, I would recommend that you discuss this with your GP.

Drugs that affect levothyroxine absorption (2)

SB writes: I have had hypothyroidism for more than 15 years and take levothyroxine. A couple of years ago my

Letters and Comments

We welcome letters from our members but please note that letters may be edited at the Editor’s discretion owing to restricted space. Please address your letters to The Editor, BTF News, The British Thyroid Foundation, 2nd floor, 3 Devonshire Place, Harrogate, North Yorkshire HG1 4AA or to editor@btf-thyroid.org, and include your membership number. Unless
Hypothyroidism and pregnancy

Alex with son Jacques

Dear BTF Jacques

I am writing to express my gratitude that you are promoting thyroid issues in pregnancy. I was diagnosed with autoimmune hypothyroidism when my son was six months old, although looking back I am sure that my symptoms began in my second trimester of pregnancy. I knew I was unwell but my symptoms were completely overlooked / dismissed despite repeated visits to the GP and an eye test for my blurred vision. (I recall a family member noticed my weight gain and breathlessness and thought I was being fat and lazy!) I found the situation very distressing, especially as I had a young baby to look after. It took me for a start fainting for an emergency GP to listen to my symptoms properly and suggest the blood test.

Earlier this summer, I contacted Practical Parenting and Pregnancy Magazine asking that they run an article highlighting thyroid issues, as in my couple of years of reading this and related magazines, I have never seen anything on the subject. There’s more to feeling tired and depressed than post-natal depression (PND); yet PND is the key post-pregnancy condition that the baby magazines focus on. Of course PND is a serious condition, but it’s not the only thing that can happen to a new mum!

I have only come across your website today and have downloaded an application form to become a member, and would look to become a more active participant in the future.

In the meantime I would ask that you keep contact with baby magazines to persuade them to get the message out there.

Warm Regards
Alex Champagne

Continued from page 11

doctor advised taking anti-cholesterol drugs but I found my body was intolerant to the first one I was prescribed. Later I was put on atorvastatin but I was feeling ill continuously and had no energy so I decided to stop. During the New Year I once again started taking atorvastatin on my doctor’s advice. Almost immediately, I lost energy, my muscles ached, I became forgetful and my skin began to flake very badly. Even my hairdresser told me something was wrong.

Then, reading chapter 7 of your thyroid cancer booklet, I realised the problem. It is so easy to continue the habit of taking medication at certain times without realising that additional treatments can cause problems. I most certainly never realised that levothyroxine should be taken four hours apart from calcium, iron, cholesterol-lowering drugs and multivitamin tablets, as these decrease absorption.

My current regime is to take ezitrol in the morning, aspirin after lunch and atorvastatin after dinner, ending with a levothyroxine tablet each night. My energy levels have increased and things are now settling down.

May I thank all of you at BTF for your excellent work and wish you well in the future. I advise anyone I meet with thyroid problems to join BTF as I have gained so much support and information over the years.

Thank you for highlighting this important issue 5B, and thanks for the compliments. We are glad you found the information in the thyroid cancer booklet helpful and that your energy levels have improved! - Ed

Asking for the numbers

DM writes: I am a hypothyroid patient of twenty years’ standing, but it’s only in the last two years, when my thyroid status has changed, that I’ve come to realise how necessary it is for doctor and patient to have a dialogue over the thyroid function blood test results.

In my experience this is not always the case. The results are often labelled ‘satisfactory’ by the doctor provided they fall within the hospital’s acceptable range without asking the patient how he or she feels on a particular dose regime. It wasn’t until I asked for, and was given, the actual results in numbers, rather than words, that I could determine at which point in the range I felt optimally well, and it wasn’t always, in my experience at least, the point at which the doctor had necessarily labelled the result ‘satisfactory’.

It seems that GPs generally regard a result anywhere within the reference range as ‘satisfactory’. I would urge all patients with this condition to be aware of the need to get the numbers and appreciate their meaning for you.

Thank you for making this important point DM – indeed, we don’t all feel well at exactly the same point in the reference range and if we are going to take thyroxine replacement for the rest of our lives it pays to learn to understand the numbers – Ed

Poem

Kate Caplan has just been diagnosed with hypothyroidism and one evening she decided to put pen to paper and write a poem about her experiences and feelings.

I know I shouldn’t moan or really whinge at all
My life is not that bad, not compared to some people

You see I feel tired, sleepy all the time,
And days roll into one
I’m constantly in a daze, no emotion and no fun

It’s not supposed to be like this, I want to be alive and energetic
I’m a 32-year-old, feeling 82, how pathetic

When I arrive home from work I eat dinner, watch TV, and wrap up with a blanket on the couch
I’m quite content with a simple life but fed up with being irritable and a grouch

To be free from pain in my neck, shoulders, right knee and left foot
Would be great
Just to have a body in a slightly better state

I really don’t want to go on but have now found out the reason
I have been diagnosed with an under-active thyroid condition, called hypothyroidism

I’ve started my medication, levothyroxine, and already feel slightly more awake
Hopefully this will be the start to feeling better, for me, for Kate

Thank you for sharing this, Kate.
Good luck from all of us at BTF and I hope you soon feel well again – Ed
If you are a child or a young person with a thyroid disorder I would like to invite you to write about yourself and your thyroid disorder and about the problems you might have had and how you have coped. You can also write in for information and advice and have your letters published. BTF has arranged for a special doctor who helps children with thyroid disorders to answer your letters in our page. You can write to me at: Children’s Editor, BTF News, The British Thyroid Foundation, 2nd Floor, 3 Devonshire Place, Harrogate HG1 4AA, or email me, Shannon@btf-thyroid.org.

Please remember to have one of your parents sign the letter too if you are under 18. - Shannon

Case study: Charlotte developed thyroid eye disease as the result of her Graves’ disease

Charlotte developed thyroid eye disease (TED) as the result of her Graves’ disease, which was diagnosed when she was seven years’ old. This is one of several case studies that will be appearing in the new BTF booklet Thyroid conditions in babies, children and young people: A guide for parents and carers. Look out for more news about the booklet!

Her parents Liz and Jon describe what it is like.

Liz and Jon: Charlotte lost a lot of weight. Clothes that had fitted her became loose and she looked very thin in her swimming costume. She also was getting taller very quickly which at first led us to think her slimming was the result of a growth spurt. Charlotte was constantly hungry although eating all the time and she became very weak, finding her bag too heavy to carry to school, and having difficulty keeping up in swimming lessons. She could not walk very far without becoming exhausted. We were always looking back and asking her to catch up.

Charlotte had a hand tremor which was not obvious at first, but we did notice her handwriting getting bigger and messier. I’m afraid before we knew what was wrong with her (and even sometimes after we did know), we were nagging Charlotte to take more care with her writing and asking why it was not as neat as it had been a few months ago.

We noticed Charlotte needed to visit the toilet in the night which she had not had to for some years. She was always hot, usually wearing t-shirts when everyone else was wearing jumpers in autumn and winter. Her heart was beating very rapidly - it could be felt when cuddling her - and she had enormous trouble resting, needing to come into our bed in the night but not really knowing what was wrong. We also noticed high emotions which were out of character for Charlotte, flying off the handle and becoming disproportionately upset.

The symptoms present very gradually, building up over time and sometimes it is someone else who notices them. I would say to other parents, don’t feel guilty for not seeing them sooner; it is very hard when you see a child every day to see the changes.

Charlotte’s Grandma suspected her symptoms were thyroid-related. We took her to the GP who agreed and arranged blood tests and an appointment with a paediatric endocrinologist. This appointment was within two weeks and the paediatric endocrinologist said he thought it was probably Graves’ disease and started her on beta-blockers (a type of drug used in managing heart rhythm disorders - Ed), then carbimazole before switching to block and replace, which has worked much better. (For an explanation of ‘block and replace’ see the Children’s Corner in BTF News 72, page 13.)

For the following couple of months we had appointments for ultrasound and nuclear medicine scans to confirm the diagnosis and get baseline measurements. The scans are very hard for a hyperthyroid child. It is difficult to stay still when you feel jittery and Charlotte and I found the radioactive injections a little bit scary.

The first 18 months were very up and down. Charlotte was sometimes stable, sometimes hypothyroid, which meant she was tired, tearful and depressed and sometimes hyperthyroid again. It has only been recently with block and replace that we have had real stability.

Charlotte’s eye symptoms are thankfully mild but ophthalmology has been a problem. Initially we saw a local ophthalmologist who knew little of Graves’ disease and had not treated children with it. She prescribed some drops for dry eyes and performed some basic eye tests. We were referred to the team at Moorfields Eye Hospital in London one year after Charlotte had been diagnosed with TED. There we saw some excellent optometrists but did not see an ophthalmologist with knowledge of TED until another year and many more visits to our local hospital had passed.

Our first meeting with an ophthalmologist with experience with TED was 29 months after diagnosis. I would very much have liked to have been able to have seen him at the beginning.

She still has mild TED, which means that her eyes are sensitive and itchy occasionally. They protrude slightly and she has double vision at the periphery.

My advice to other parents would be try not to feel too guilty about how much you have nagged your child to pay attention, keep still, improve their writing, keep up on walks etc. Now that you know it was the hyperthyroidism, you can put your energy into talking to them as much as you can and helping them to understand what they are feeling and not into beating yourself up!

Expect some grieving at the start. It can take a while but your child will get better with the medication. We found taking in the diagnosis and the changes it brings in your child very hard and upsetting at first but Charlotte is much, much better now.

Remember to explain to your child’s school about the condition. While they are hyperthyroid, your child may need extra snacks at school.

Take time to learn about the condition and the medicines. I recommend joining the British Thyroid Foundation. In BTF News recently there was an excellent explanation for children of thyroid disease (my husband also found it helpful) and insight from Shannon, Children’s Editor, who I think has had similar experiences to Charlotte, in Children’s Corner.

Charlotte, aged 10, writes: When I was ill, I felt overactive, dizzy and restless. I was very hot and sweaty and got tired very easily when I went swimming. I was also hungry and thirsty all the time. I had trouble sleeping because I was hot and restless and kept having to go to the loo at night! I could also get angry very easily. At school, I found that words jumbled up on the board and it strained my eyes. My eyes were sensitive and itchy and watered in the wind.

Now I feel strong and healthy and I have a normal appetite. I’m a normal size, I sleep well and school work is easier.

My eyes still water and I still get double vision if I look out of the side of my eye, like when I look out of the car window. I still get angry as well.

My advice to someone with a thyroid condition is to count to ten when you are angry and tell your friends how you feel so they understand you are not cross with them. You also need to explain to your school what is wrong and work out what to say when people ask about your neck or eyes being different.

Trust the doctors - the medicines will make you feel better.

Merry Christmas and a Happy New Year
Local Groups

Please check the BTF website for the latest details about forthcoming meetings: www.btf-thyroid.org

Birmingham

Our September meeting was held at the Morris Centre, Queen Elizabeth Medical Centre, Birmingham. Approximately twenty people attended starting with registration (thank you Alison) and refreshments (thank you Susan and Peter). Also thanks to Nigel, Neil and Tanya who provided help and support throughout the afternoon.

Dr Kristien Boelaert, who is a Medical Research Council Clinician Scientist at the University of Birmingham and Consultant Endocrinologist at the Queen Elizabeth Hospital, Birmingham, gave a talk on ‘Thyroid Cancer - Causes, Treatments, Side Effects and Recurrence’ followed by a Q&A session. The presentation provided a vast amount of information with her very interesting Powerpoint presentation. Dr Boelaert has agreed to her presentation being distributed, and I am happy to send it via email upon request. I have converted her power point presentation to PDF for those who do not have Microsoft Office.

Dr Boelaert’s presentation provides details of the classification and known causes of thyroid cancer, survival rates, the different treatments and risk factors associated with the different classifications. The final slide concludes:

- Thyroid nodules are common - thyroid cancer is rare
- Most thyroid cancers are differentiated and have a good prognosis
- Surgery, radioiodine and TSH suppression form cornerstones of management
- Easy monitoring through tumour markers. Novel new therapies on the horizon

Dr Boelaert followed the presentation with a Q&A session which was not restricted to thyroid cancer. Dr Boelaert joined the group for refreshments afterwards and continued to answer questions on a one-to-one basis. Feedback from the evaluation forms, via email and comments on the day were akin to ‘I thought Dr Boelaert was a brilliant speaker. I found it very informative.’ Many thanks to Dr Boelaert.

Our 2011 meetings will be held on Saturdays, from 2 to 4pm at Yardley Baptist Church, Rowlands Road, Birmingham B26 1AT.

2 April 2011 - Dr Andrew Bates, Consultant Physician Endocrinologist Birmingham Heartlands and Solihull NHS Trust, will talk about under-active thyroid.

2 July 2011 - Kelly Stringer, ENT Nurse and complementary therapist, Queen Elizabeth Hospital, Birmingham, and Desmond McGuire, ENT/Maxillofacial, Head & Neck Counsellor, Queen Elizabeth Hospital, Birmingham, will discuss complementary treatments.

19 November 2011 - Dr Neil Gittoes, Divisional Director, Div 3 and Consultant Endocrinologist, Queen Elizabeth Hospital Birmingham will talk about over-active thyroid – Janet

Bolton

Mr Simon Hargreaves, ENT Surgeon, Royal Bolton Hospital spoke to us about thyroid surgery in November. There will be a report in the next issue.

Our next meetings will be on Saturday 12 March, Saturday 11 June and Saturday 12 November from 10am until 12 noon at The Barlow Institute, Bolton Road, Edgworth, Bolton. Speakers to be announced.

At the March meeting there will be details of the Garden Open Day in aid of BTF to be held in the Ribble Valley near Clitheroe on Sunday 22 May.

Please contact me for any further information, help or advice on 01204 853557 or e-mail inghamcaz@aol.com – Carole

Durham

The third meeting of the local BTF Durham Group took place at Durham Country Hall on 25 September and was very well attended. The guest speaker from the Royal Victoria Infirmary in Newcastle was Professor Simon Pearce who gave an excellent presentation on hypothyroidism. Discussions took place over the ideal TSH level that should be achieved and tips on how best to take your medication and what drugs interfere with the absorption of the levothyroxine. The presentation received excellent feedback from the group with comments that it was very informative.

I would like to thank Professor Pearce for taking the time to come along to speak to the group and all those who attended and provided the feedback.

Our first meeting in 2011 takes place on 26 February at 10am in Committee Room 1B at Durham County Hall. The speaker is Dr Sue Jones, Consultant from Hartlepool General Hospital. Details of other meetings in 2011 will be posted on the BTF website and appear in the next newsletter – Jennifer

Edinburgh

At our October meeting we had an open discussion about thyroid support. At the time of going to press we’re planning to meet in December when Dr Peter Henriksen, Consultant Cardiologist, Western General Hospital in Edinburgh, is speaking about thyroid disease and the cardiovascular system.

The Edinburgh Group continues to meet in Liberton High School, Gilmerton Road, Edinburgh at 7.15pm on the last Tuesday of each month except for the school holidays – Margaret

Hereford

The BTF Hereford Group held its first meeting under a new format. There was a wonderful turnout despite the terrible weather. Janis Hickey and Donna Reed from BTF HQ came and gave us a very interesting talk about the work that the BTF does. Thanks to Janis and Donna for helping to make the meeting a success.
Everyone left with a very positive attitude and looking forward to the next meeting in November when at the time of going to press, Alison Wagorn, Consultant Endocrine Surgeon, from the Royal Liverpool and Broadgreen University Hospital, was due to give a talk about thyroid disease, thyroxine replacement and thyroid cancer.

In April 2011 Lynn Adams, a nutritional therapist will be meeting with us to help us with diet and nutrition. Steve Newby from the Chinese Martial Arts Club will be giving us a talk and demonstration on Tai Chi, an ancient Chinese exercise programme of gentle stretching and moving. Details will be posted on the BTF website nearer the time.

Our meetings take place from 7-9pm at The Point 4, Venns Lane, Hereford, HR1 2DT, opposite the Blind College. A small charge of £2 is requested to pay for beverages – Denise

Manchester and Salford

For personal reasons I have unfortunately had to put the plans for a December meeting on hold. I will provide details in the next edition of the BTF news and on the website about the group and future meetings in 2011 – Nia

Milton Keynes

There will be a report of the September and December meetings in the spring edition of the BTF News. For further information please check the BTF website or call me on 01908 562740 or see our local group’s website www.thyroidmk.co.uk – Wilma

Newcastle upon Tyne and North Tyneside

Dr Asgar Madathil, Endocrine Research Registrar at the Queen Elizabeth Hospital, Gateshead, spoke at our recent meeting on ‘Fatigue in Subclinical Hypothyroidism’. At the well-attended meeting, Dr Madathil gave a fascinating and clear account of his ongoing research project into the problems of fatigue. He generously answered many individual questions. We hope he will return with his findings when the project is complete.

Our next meeting will be on Saturday 26 March from 10am to 12 noon at The Berwick Hall, Level 2. Newcastle City Library, 33 New Bridge Street West, Newcastle upon Tyne (five minutes’ walk from the Monument Metro). The speaker will be Professor Simon Pearce, Consultant Endocrinologist, Royal Victoria Hospital, Newcastle upon Tyne. To book a place, please contact me between 4-6pm on: 0191 253765 or email Judith@dryhurst.co.uk. The suggested entrance donation is £2.50 to cover room hire costs – Judith

Notts/Derby

We had an enjoyable evening at our October meeting. Reflexologist Lynne Rowbottom gave a presentation and demonstration on the benefits of reflexology and how reflexology may help those living with a long-term health condition and the benefits of relaxation. Lynne was quick to point out that the reflexology was not a cure for thyroid disorders. Fourteen members attended the meeting and preparations were made ready for a thyroid awareness meeting at Kings Mill Hospital in November – Bridget

London calling!

A London-based BTF member is interested in setting up a BTF group in London - see www.thyroid-hope.blogspot.com. Please contact us at BTF HQ (contact details on the back page of the newsletter) or by emailing ie@btf-thyroid.org and let us know if you are interested in attending an inaugural meeting in February/March 2011 and if you would like to help out with the group. Please mark your envelope or email ‘London meeting’. Thanks!

Questions about Addison’s?

We regret that the telephone number for the Addison’s Disease Self-Help Group (ADSHG) printed on page 14 of BTF News 74 was incorrect. The correct phone number of the ADSHG is: 0844 588 2722.

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:
Maria Altken
Clare Balding OBE
Jenny Pitman OBE
Melissa Porter BA (Hons)
Dr W Michael G Tunbridge MA, MD, FRCP
Gay Search

Trustees:
Mr Scott Brady LLB MBA
Professor P Hindmarsh BSc MD FRCP
FRCPC
Mrs C Ingham
Professor JH Lazarus MA MD FRCP
Mr Geoffrey E Rose BSc MS DSc MRCP
FRCS FRCOphth
Dr M Strachan MD FRCP (Edin)
Mrs Judith Taylor BA (Hons)
Mrs Dianne Wright RGN BSc (Hons).

Ex-Officio Members of the Trustees:
Professor J A Franklyn MD PhD FRCP – President, British Thyroid Association
Mr Greg Sadler MD FRCS - Secretary, British Association of Endocrine and Thyroid Surgeons

Solicitors:
McCormicks Solicitors,
Wharfedale House, 37 East Parade,
Harrogate HG1 5LQ.
Tel. 01423 530630

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.
OFFICIAL BTF LOCAL COORDINATORS
Our coordinators will also be happy to take general calls on all aspects of thyroid disorders

**Birmingham**
Janet (PC,CS,RIC) 0121 6287435

**Manchester & Salford**
Nia (U) 01942 819195

**Bolton**
Carole (FC,CS,RIC) 01204 853557

**Milton Keynes**
Wilma (U) 01908 562740

**Durham**
Jennifer (U) 0191 5693578

**Newcastle upon Tyne & North Tyneside**

**Edinburgh**
Margaret (PC) 0131 6647223

**Notts/Derby**

**Hereford**
Denise (O,RI,U) 01432 271561

**Bridget (GR,TS,UPH)** 01623 750330

---

OFFICIAL BTF TELEPHONE CONTACTS

<table>
<thead>
<tr>
<th>Name</th>
<th>Phone Number</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Penny</td>
<td>(Ch) 01225 421348</td>
<td>Wilma (U) 01592 754688</td>
</tr>
<tr>
<td>Debby</td>
<td>(Ch) 0208 9597257</td>
<td>Joan (U) 01865 730919</td>
</tr>
<tr>
<td>Dave</td>
<td>(PC,CS,RAI) 07939 236313</td>
<td>Angela (U) 01943 873427</td>
</tr>
<tr>
<td>Jackie</td>
<td>(PC,CS) 01344 621836</td>
<td>Sheryl (U) 02920 610090</td>
</tr>
<tr>
<td>Fiona</td>
<td>(C,HCN,CS,RAI) 01926 853312</td>
<td>Bob (U) 01202 722784</td>
</tr>
<tr>
<td>Christopher</td>
<td>(PC,FC,CS,RAI) 01840 213171</td>
<td>Richard (U) 01483 576874</td>
</tr>
<tr>
<td>Sue</td>
<td>(PC,CS,RAI) 01909 732476</td>
<td>Olwen (O,RI,U) 01536 513748</td>
</tr>
<tr>
<td>Gay</td>
<td>(G,TS) 0208 8489101</td>
<td>Lucy (GR,RI,U) 0117 9424396</td>
</tr>
<tr>
<td>Collette</td>
<td>(U,ITS) 01695 721281</td>
<td>Jane (GR,RI,TED,G,U) 01737 352536</td>
</tr>
<tr>
<td>Brenda</td>
<td>(U) 01908 502214</td>
<td>Peter (TED,GR) 01200 429145</td>
</tr>
</tbody>
</table>

---

**KEY**
- 9am to 5pm only
- 4 to 6pm Mon, Tues, Wed
- Not available to take calls
- After 6pm weekdays and anytime weekends
- 7 to 9.30pm
- 10am to 12 noon weekdays
- 4 to 6pm Mon, Tues, Wed
- Not available to take calls

<table>
<thead>
<tr>
<th>Key</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ch</td>
<td>Thyroid disorders in children</td>
</tr>
<tr>
<td>C</td>
<td>Cancer of the thyroid</td>
</tr>
<tr>
<td>FC</td>
<td>Follicular cancer of the thyroid</td>
</tr>
<tr>
<td>PC</td>
<td>Papillary cancer of the thyroid</td>
</tr>
<tr>
<td>HCN</td>
<td>Hürthle Cell Neoplasm</td>
</tr>
<tr>
<td>CS</td>
<td>Thyroid cancer surgery</td>
</tr>
<tr>
<td>RAI</td>
<td>Radioactive iodine (I-131) ablation</td>
</tr>
<tr>
<td>G</td>
<td>Goitre</td>
</tr>
<tr>
<td>TS</td>
<td>Thyroid Surgery (non-cancer)</td>
</tr>
<tr>
<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>
</tr>
<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>
</tr>
</tbody>
</table>

---

**OUR PARTNER ORGANISATIONS**

**AMEND** – Information on medullary thyroid cancer. Contact: Jo Grey 01892 516067 email: info@amend.org.uk website: www.amend.org.uk

**Hypoparathyroidism (HPTH) UK** – an organisation providing information and support about all types of parathyroid disorders. Contact: Liz Glenister email: liz@hpth.org.uk website: www.hpth.org.uk. HPTH Helplines 01342 316315 (South) and 01623 750330 (North)

**Thyroid Cancer Support Group – Wales** 08450 092737 email: thyroidgroup@tiscali.co.uk website: www.thyroidsupportwales.co.uk

**Butterfly Thyroid Cancer Trust** – is 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 Farnell 01207 545469 email: enquiries@butterfly.org.uk website: www.butterfly.org.uk

**Cancer52** – an alliance of organisations working to improve outcomes for patients affected by less common cancers website: www.cancer52.org.uk

**Thyroid Eye Disease Charitable Trust**: TEDct, PO Box 1928, Bristol BS37 0AX. 0844 8008133 email: ted@tedct.co.uk website: www.tedct.co.uk

**British Thyroid Association** website: www.british-thyroid-association.org

**British Association of Endocrine and Thyroid Surgeons** website: www.baets.org.uk

**Sense about Science** website: 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: 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’.

**Director and Secretary to the Trustees:** Mrs J L Hickey
**Treasurer:** Mr A B Menzies
**Computer Manager:** Professor B Hickey
**Webmaster:** Claire Skafe
**PA to the Director and Office Manager:** Mrs C McMullan
**email:** c.mcmullan@btf-thyroid.org
**Administrative Assistant:** Jennifer Linney

**Project Facilitator:** Donna Reed
**Editor:** Judith Taylor email editor@btf-thyroid.org
**Medical Editor:** Dr P Perros
**Children’s Corner Editor:** Shannon Davidson email Shannon@btf-thyroid.org
**Head Office Volunteers:** Jan Ainscough, Angela Hammond, Vivienne Rivas, Pam Cowburn, Tracy Chandler, Katharine Jeans, Nick Balmforth, Angela Ward, Nikki Brady
**Design and artwork for BTF News:** Keen Graphics 01423 563888

Next issue of BTF News: spring 2011. Letters and articles should be sent to the Editor, BTF News by 31 January 2011. News from local groups should be sent in to the PA to the Director to arrive by 7 February 2011.

For on-line donations please visit www.justgiving.com/btf/donate

Copyright © 2010 British Thyroid Foundation. All rights reserved. No part of this publication may be reproduced, stored in a retrieval system or transmitted in any form or by any means without the prior permission of the copyright owner.