Celebrating 125 years of thyroid hormone replacement

Endocrine specialists and delegates from as far afield as Australia and the USA converged on Newcastle in May to celebrate 125 years of thyroid hormone replacement at a meeting organised by the British Thyroid Association (BTA) and Newcastle University.

This two-day event (also incorporating the 64th meeting of the BTA), packed with talks by renowned endocrinologists on research and possible new treatments in endocrinology and diabetes, included a ‘symposium’ on thyroid research and possible new therapies which was chaired by two BTF Trustees - Dr Petros Perros and Dr Mark Vanderpump.

Amongst other things, delegates at the meeting discussed 21st Century issues with thyroid hormone replacements.

Professor of Clinical Diabetes and Metabolism at Cardiff University, Colin Dayan who spoke at the event said: ‘Dr Murray’s discovery (see below) of thyroid hormone replacement was certainly groundbreaking. But 125 years on, there are still many unanswered questions - such as how much thyroid hormone is ideal for pregnancy, or in children; and do blood levels really tell us whether there is enough thyroid hormone within the body’s cells?’

‘With over five million thyroid blood tests every year and more than one million people taking the hormone, these are still important questions for a large number of people.’

Who was George Murray?

Dr George Murray was a young doctor from Newcastle who, in 1891, injected an extract from a sheep’s thyroid gland into a patient with symptoms of thyroid under-activity and noticed an improvement in the patient’s symptoms. Once thyroid hormone was found to work by Dr Murray, many other forms of hormone replacement were subsequently developed, such as insulin for diabetes and oestrogen hormone replacement for the menopause.

See page 8 for an article by Dr Stefan Slater who gave a fascinating talk at the meeting about the history of the discovery of thyroid hormone replacement.
Levothyroxine tablet survey

One of the BTF’s projects is to support people with hypothyroidism, and to collect and reflect their views in order to help improve patient care. An effective way of doing this is to host a survey. Amidpharm Mercury (AMCo) prepared an online levothyroxine tablet survey that was hosted on the BTF website from 3 December 2014 to 15 February 2015. The survey was anonymous and conducted in line with the Data Protection Act and all the ethical policies that apply to surveys of this kind in the UK.

There were 16 questions, which were all optional, and respondents had the opportunity to add free text comments. Questions (1) to (4) were answered with a single response from a pre-defined list of possible answers. The total numbers of respondents was 1,644 and a summary of the results of the survey is available on the BTF website www.btf-thyroid.org.

Pregnancy trial now closed

The tablet trial (Thyroid Antibodies and LEvoThyroxine) has now closed to recruitment; the TABLET team have surpassed their target and recruited 952 women into the trial. Results from the trial will be available in spring 2018. They will spend the next 18 months following up women and their pregnancy status. The team would like to thank everybody for their support.

Recycling for good causes

Thank you to everyone who has sent in their unwanted items. So far we have raised over £50. If you have more items to donate and would like additional freepost labels please email fundraising@btf-thyroid.org.

Thyroid cancer conference

Join the Butterfly Thyroid Cancer Trust for the first UK thyroid cancer conference for patients.

Where: Royal Society of Medicine, 1 Wimpole Street, London W1G 0AE

When: Monday 5 December 2016 12-5pm

Cost: Free! Lunch and afternoon tea provided.

At the forum you will have the chance to meet other patients, listen to leading experts and have the opportunity to ask questions. To book your place email: enquires@butterfly.org.uk

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Carole Ingham

It was with great sadness that we learnt of the sudden death of Carole Ingham, BTF Trustee, just a few days after she attended the Trustee Away Day meeting in York in January.

Carole became involved with the BTF in 1999, as a local coordinator for the Bolton group. The group first met in November 1999 and Carole ran it successfully until 2013, when she became a telephone support contact. Carole was a trustee on two occasions and Chair of Trustees between 2009 and 2012. She was the BTF thyroid cancer group lead for several years, playing an instrumental part in the preparation of the first edition of the BTF booklet ‘Thyroid Cancer: For Patients, By Patients’, which brought together patients who wished to share their experiences of thyroid cancer.

She also helped revise further editions. Carole represented the BTF at numerous conferences and meetings, including the Yorkshire, the Manchester and Cheshire Cancer Networks and Cancer52. She represented the BTF at numerous conferences and meetings, including the Yorkshire, the Manchester and Cheshire Cancer Networks and Cancer52. She also helped to organise many BTF information events. Carole lost her husband, Ian, in 2014, but she remained actively involved in the BTF.

We will remember her as a person committed to supporting people with thyroid disorders, in particular thyroid cancer.

After Carole’s funeral, her family - Alison, Winston, Janet, Kevin, Stuart and her godchildren Terri and Liam sent special thanks to Janis Hickey for helping her friends and family understand the enormous commitment and dedication that Carole showed to the BTF. They also thanked the BTF for the floral tributes and kind messages from BTF members.

News from BTF

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Office enquiry line open: Mon to Thurs, 11am - 2pm. In the event of a complaint, please address your correspondence to ‘The Chair of Trustees’.

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Next issue of BTF News: October 2016

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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.
Pay by standing order and save money!

Paying your membership by standing order is the most cost effective way to pay for your BTF membership. It also helps us to keep costs down. Please email membership@btf-thyroid.org for a standing order form or call the office on 01423 810093 and ask us to send you one.

Calling all longstanding members

Unbelievably, it will be the BTF’s 25th Anniversary in October! We would love to include stories from members who have been with us from the start (or for a while!). Please get in touch and tell us about your support for BTF, how you first heard about the charity, how you’ve been involved and how the BTF has helped you. Write to the office or email e.clegg@btf-thyroid.org.

Office move

We are now settled in our new offices. We would particularly like to thank Tim and Cath Culligan and Bryan Hickey for all their help with the set up of the new telephone system and computers. We’re also grateful to Naish Estate Agents and Solicitors in York for their conveyancing services, which were kindly provided free of charge. Our new address is: Suite 12, One Sceptre House Hornbeam Square North, Hornbeam Park Harrogate HG2 8BP. Our new phone number is 01423 810093.

The changing face of the BTF

When BTF was established in 1991 there was very little information available to help thyroid patients understand more about their disorder. There was no internet of course and people had to become members of the BTF to receive the information we produced. It was entirely due to the loyalty of members that the BTF was able to grow and is the thriving and well-respected organisation that it is today.

Fast forward 25 years and how the world has changed! Did you know that in the last 12 months we have had over 1,691,000 hits to the BTF website? This compares to just 438,000 hits in the same period three years ago. Of course we are delighted that so many more people get support from the BTF but the downside of this growth is that fewer people feel the need to become BTF members. In 2005 there were over 5,800 members who brought an income of almost £79,000; in 2016 there are about 3,800 who bring an income of just £48,000.

In line with the BTF’s charitable objectives our trustees believe that raising the profile of thyroid disorders and educating the public is a vital part of the work we do. To that end we will continue to develop our resources and are committed to making them freely accessible on the website. To make this possible however, and to ensure we are not overly reliant on membership income, it’s vital that we seek out and develop new sources of funding.

If you have any suggestions about fundraising or would like to contribute in any way please phone 01423 810093 or email fundraising@btf-thyroid.org.

ChariTable Bookings

The BTF has signed up for the ChariTable Bookings restaurant reservation App (iphone only at present). This allows customers to book tables at thousands of participating restaurants across the UK. At no cost to the customer, £1 for EVERY diner will be kindly donated by the restaurant to the BTF. Simply download the ChariTable app on your iphone and book your favourite restaurant knowing that you’ll be supporting the BTF while you eat!

Easy way to donate to the BTF

Payroll Giving is a flexible scheme that allows anyone who pays UK income tax to give regularly and tax-free to the charities and good causes of their choice. Payroll Giving donations are deducted before tax so each £1.00 you give will only cost you 80p, and if you’re a higher rate tax payer it will only cost you 60p. Payroll Giving (also known as ‘Give As You Earn’ or ’workplace giving’) is a valuable, long term source of revenue, providing regular income to help charities budget and plan ahead more effectively. It’s cheaper because it’s tax free - for example, a donation of £5 per month costs the basic rate tax payer £4.00 (the taxman pays the rest!). It is also the only way for higher rate taxpayers to pass on their 40% or 45% tax to charities. Only 28% can be recouped via other ways of giving.

Go to www.payrollgiving.co.uk for more information.
**Out and About**

**International meeting held to identify early signs of Graves' disease and eye problems**

Janis Hickey, BTF Founder, attended a three-day meeting of experts involved in the INDIGO (Investigation of Novel biomarkers and Definition of the role of the microbiome in Graves’ Orbitopathy) project and EUGOGO (European Group on Graves’ Orbitopathy) in Cardiff in April. The meeting included feedback from people with Graves’ disease and thyroid eye disease on the final afternoon. Following a fascinating description of a study into the effect of probiotics on the gut - the subject matter of the INDIGO trial study - presented by Professor Colin Hill of Cork University, Lynne Kyffin, a TED patient from Newcastle, gave an equally fascinating talk entitled: **Are You What You Eat?** Lynne described life events and illnesses she had experienced over many years and how, by researching her eating habits and food content, and subsequently adjusting her diet, felt far healthier than she had for the past three decades.

A patient group was asked to discuss whether the presentations would lead them to reflect on how else they might deal with their thyroid disorder or TED, and whether instabilities in their gut may have caused their thyroid disorder. Janis Hickey presented a summary to the conference participants: most patients were unsure whether they would make any changes to their diet, but a couple pondered whether being vegetarian for three decades might have had adverse effects, and whether alcohol had a part to play. It had been clear from Lynne’s presentation that she had found information lacking on precisely what dietary changes to make, and it was felt more research and evidence was needed before an awareness campaign could be conducted. The patient group agreed that it would be helpful to organise a questionnaire about lifestyles, life events and diet.

**Professor Marian Ludgate**, coordinator of INDIGO, commented: ‘The patient group are absolutely right in saying that more studies need to be done. As part of the INDIGO project, patients recruited are asked to complete a questionnaire about their diet and lifestyle habits, in addition to providing various samples for analysis. We hope that this will prove to be informative and eventually lead to better care for people with TED.’

For further information about the INDIGO research study see: [www.indigo-iapp.eu](http://www.indigo-iapp.eu/)

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**In the Media**

**Europe bans two endocrine-disrupting weedkillers**

The European Commission has ordered a ground-breaking suspension on two endocrine-disrupting weedkillers that have been linked to thyroid cancer, infertility, reproductive problems and foetal malformations, as reported in *The Guardian* on Tuesday 19 April 2016.

The article explains: ‘The use of Amitrole and Isoproturon will now be banned from 30 September 2016 across Europe, after an EU committee voted unanimously for the first ever ban on endocrine-disrupting herbicides. Endocrine disruptors are chemicals that can interfere with the hormone system. Scientific studies indicate that they can cause cancerous tumours, birth defects and a range of ailments related to gender, sex and reproductive systems.

Hans Muilerman, chemicals officer at Pesticide Action Network (PAN) Europe, said: ‘This is a historic decision as it is clear that these chemicals are 100% endocrine disruptors. We applaud these two proposals but at the same time note that a large reservoir of harmful, classified and endocrine-disrupting pesticides is still waiting for a decision, which has been repeatedly postponed by the commission.’

Amitrole, also known as aminotriazole, is widely used in 10 EU countries, including the UK, in industrial farming. But a European Food Safety Authority (EFSA) analysis found that it was an endocrine disruptor that could damage unborn children, and have toxic effects on the thyroid and on reproductive organs’.

Source: [http://gu.com/p/4te8g/sbl](http://gu.com/p/4te8g/sbl)
BTF Projects Update

The BTF is currently focusing on several key thyroid related areas with the aim of improving knowledge, assisting with research and improving the patient’s experience. We are developing strategies for hypothyroidism care, iodine deficiency and subsequent thyroid problems, children with thyroid issues, thyroid cancer and thyroid eye disease. Each project group meets regularly to discuss progress, although we do not always have updates available for every newsletter.

Iodine project

International iodine meeting

Janis Hickey, BTF Founder, attended a meeting organised by the Iodine Global Network (IGN) in March. The meeting focused on the role of iodine in pregnancy, the issue of mild-to-moderate iodine deficiency in the UK, and how pregnant women living in this environment unknowingly place their children at possible risk of impaired intelligence and learning disabilities.

The IGN emphasised the importance of people with normal thyroid function having sufficient iodine levels, both before and during pregnancy, as well as during breast-feeding. There was also discussion of possible solutions to remedy this situation: the iodisation of salt; or iodine supplementation before and during early pregnancy and breast-feeding. The meeting highlighted the fact that according to The World Health Organisation (WHO) the UK is shown to be one of the top ten iodine-deficient countries in the world. WHO has produced recommendations for the management of iodine deficiency, yet various UK-based studies show that pregnant women and women of child-bearing age have levels below the level recommended by WHO. The IGN concluded that considering the evidence to date, ideally a randomised controlled trial (RCT) is now required to investigate iodine deficiency in pregnant women and cognitive outcomes in their children.

Thyroid cancer

We are in the final stages of updating our thyroid cancer booklet: Thyroid Cancer For Patients, By Patients. The unique emphasis about this publication is that it includes much helpful information that has been contributed by patients. If you would like to share your experiences (even if it is simply a couple of sentences about how you felt at any stage of your own thyroid cancer journey) please email julia.priestley@btf-thyroid.org. We would love to hear from you!

Children

BTF involvement in possible new treatment for Graves’ disease in children

The BTF is closely involved in the conduct of a new study looking to see if a trial drug called Rituximab will slow down or stop the thyroid gland making too much thyroid hormone in children. This trial will see if Rituximab can help make young people with Graves’ disease better when it is used together with a short course of carbimazole.

Dr Tim Cheetham from Newcastle University’s Institute of Genetic Medicine and BTF Trustee is leading a trial to find a cure for Graves’ in young people. In Graves’ hyperthyroidism the thyroid produces too much thyroid hormone. Patients with this condition can have tiredness, sleeping problems, poor concentration and weight loss. It is difficult to treat Graves’ in the young because the tablets available (carbimazole) have a number of side effects and yet do not usually cure the condition. Only 25% (one in every four) 12-20 year olds will be permanently better after a standard two year treatment. Other ways to treat this disease include surgery and radio-iodine. Surgery and radio-iodine can have significant risks and are not a cure because patients that have surgery or radio-iodine need to take thyroid hormone replacement. Rituximab is a medicine that is already used in other autoimmune conditions, such as rheumatoid arthritis. We will keep you up to date with the progress of this trial.

The BTF website has a wealth of information on thyroid disorders and children - go to www.btf-thyroid.org/projects/children

Thyroid eye disease

Experts at the meeting referred to foods such as dairy products and fish that are high in iodine but also pointed out that studies show that the levels of iodine vary widely in both. Organic milk for example has far less iodine content than conventional milk. Experts warned that despite the existing evidence and WHO recommendations that supplements should be made available in countries where pregnant women cannot access iodised salt, the last guidelines from the UK Government on iodine status were issued in 1991. They emphasised that more evidence is required and so too is the political will to promote a policy change to protect unborn children from the harmful health effects of low iodine.

The well-respected medical publication The Lancet Diabetes and Endocrinology published editorial comment following the meeting. Go to: www.thelancet.com/pdfs/journals/landia/PiIS2213-8587(16)30055-9.pdf

Experts at the meeting about this publication is that it includes much helpful information that has been contributed by patients. If you would like to share your experiences (even if it is simply a couple of sentences about how you felt at any stage of your own thyroid cancer journey) please email julia.priestley@btf-thyroid.org. We would love to hear from you!
Fundraising and Donations

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

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

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

Fundraisers

Sixteen year old Amber Burns has raised a fantastic £75 by holding a cake sale at her school. Amber had a total thyroidectomy last year. She is planning to organise a sponsored walk later in the year.

Lottie Brand raised nearly £400 by holding a sponsored silence for seven days - quite a challenge! Lotty explained her reasons for the challenge: ‘Before Christmas I had half of my thyroid removed and one of the risks of this surgery was temporary or permanent voice loss. This did make me seriously ponder what it would be like to lose the use of my voice. I wanted people to think about the things we all take for granted’.

Joanne Lewis raised £44 for the BTF by running the Coventry Half Marathon.

Eleven year old Aarabi Keteeswaranathan raised £30 by selling cards she had made to her friends and relatives.

Corinne Neill and a group of her friends and family climbed Ben Nevis in June (in a heat wave!) in remembrance of Corinne’s sister Gwen who recently passed away after battling thyroid cancer. They have raised over £700 so far to support the work of the BTF in Gwen’s memory.

Gwen’s family also donated £470 from a collection held at her funeral and Corrine’s husband Graham nominated the BTF for a recent charity day held by Caddies at Muirfield Golf Club and raised an amazing £1520.

The Inner Wheel Club of Ipswich Orwell chose the BTF as their charity of the year. Linda Smith, their President who has an underactive thyroid helped organise a garden party and raised over £500. Over the year the group has managed to raise over £1000 for the BTF!

Lottie Brand

Future Fundraisers

Rachael Harrop is taking part in the York 10k in August. She was diagnosed with an underactive thyroid four years ago. www.justgiving.com/Rachael-Harrop1

Steve Foulkes is cycling from London to Paris in September 2016 for the BTF. www.justgiving.com/steven-foulkes

Natalie Ryan is running her first 10k in September when she takes on the Hursley Multi-terrain Race in Hampshire. Natalie had a thyroidectomy 15 years ago and has found subsequently having an underactive thyroid challenging.

Great North Run

We have five runners in the Great North Run in September - Adam Perros, Martin Priestley, Mo Bhaskaran, Liz Killean and Marika Wiebe-Williams www.justgiving.com/fundraising/Marika-Wiebe-Williams

This is the first time we have taken places in this iconic race - look out for photos in the next BTF News!

Donations

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

Donation of £350 from Mrs Squires and Mrs Searles.

Donation of £100 from DK Cookson.

Donation of £100 on behalf of the BBC in memory of Adam Beck, a make-up artist who suffered from a thyroid disorder.
**My Story**

**Chloe** was diagnosed with congenital hypothyroidism (CHT) when she was born. Chloe’s mum Emma explains the rollercoaster ride from that diagnosis:

Chloe had her heel prick test at five days old at home, without any problems and we forgot about it. It wasn’t until the following week that we discovered the heel prick test had proved vital, when the community midwife paid a visit. We thought she’d come to see how Chloe and myself were, as I’d had a c-section and breastfeeding hadn’t worked out. But she’d come to tell us Chloe might have congenital hypothyroidism. Having not paid much attention to the heel prick test information, we thought Chloe had some life threatening disease and were devastated. The midwife explained this wasn’t so and that she’d made us an appointment with a doctor in the children’s department at the local hospital.

At first I had a blood test along with Chloe, to see if it was me that had the underactive thyroid and Chloe may have been carrying it still from being inside me. Not the case though, and so it began! Her doctor explained congenital hypothyroidism (CHT) very clearly to us, answering any questions we had. It was then that we realised it was easily treated and that Chloe could lead a normal life. There were many trips to the hospital in the first few months of Chloe’s life, blood tests a-plenty to get the levothyroxine dose correct.

At first, we crushed the tablet and put the bits of tablet in a little of her milk on a teaspoon and she happily swallowed it. It did seem a bit of a palaver at first, but we all got used to it and it became routine to her, the norm. I think Chloe was around two when she first took the tablet by herself. She surprised us by just popping it on her tongue and sometimes crunching it. To this day (aged 10) she still just pops it in her mouth at breakfast time.

When Chloe got to the chubby baby stage, with the folded bits of skin that they have to grow into, finding a good clear vein on her hand or arm became a problem. For a time we had to visit the children’s ward at our hospital for her blood tests, as there were plenty of staff around who were used to children. But no matter how many staff, she would struggle and scream. By the time she was one, I was a dab hand at applying the numbing cream and dressing, and at restraining her. And by the time the children’s ward decided she was old enough to attend the blood clinic (about five years old) I had to plan going so my husband could come too. Chloe on my lap with my arms cuddling (firmly!), keeping her upper body still, husband helping one nurse with the arm the blood was to be taken from whilst another nurse took the blood! It wasn’t till Chloe was about seven that things improved. My husband and myself had been invited for an over-40 health check, which involved a blood test each. I had a light-bulb moment, and said Chloe should come, come and see that we don’t scream and struggle. And as luck would have it, she was due a blood test shortly after. She just winced and cried a little. And by the next blood test, she hopped in the chair herself! There is also a very important someone who comes along to the blood tests too. Chloe’s favourite and most loved cuddly, Ducky. We couldn’t do without Ducky support!

Chloe was taken off levothyroxine at three, to see if her thyroid would ‘kick in’. Her doctor had always told us this was the age to do it, as much rapid growth had taken place by that age. After six weeks or so we’d noticed Chloe had begun to slow down, lethargic, not eating well, and a blood test confirmed her thyroid still wasn’t working, and she would be on levothyroxine all her life.

In April 2014, we attended the BTF Children’s Conference. It was great for Chloe to meet other children who pop a tablet everyday like her. We’ve yet to meet anyone locally who has CHT. But Chloe takes it all in her stride, it’s the norm to her and we plod along happily with her. Despite the struggles with the blood tests for a few years, we’ve had a good journey so far, with a great doctor and staff at the hospital who are informative, caring and understanding.

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‘**Having not paid much attention to the heel prick test information, we thought Chloe had some life threatening disease and were devastated.**’

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International Thyroid Awareness Week 2016 was celebrated around the world from 23-27 May. This year’s campaign aimed to raise the profile of thyroid disease and how it affects children and babies. [www.thyroidweek.org](http://www.thyroidweek.org)

We have lots of information to help parents and children on the BTF website. Go to [www.btf-thyroid.org/projects/children](http://www.btf-thyroid.org/projects/children)
A complete transformation:
The 125th anniversary of the discovery of thyroid hormone replacement

The 125th anniversary of the discovery of thyroid hormone replacement for an underactive thyroid gland in 1891 by Dr George Murray of Newcastle was celebrated on 12 May. Doctors and patients world-wide had good cause to celebrate, for the achievement marked the birth of clinical endocrinology and was followed over the years by many hormone discoveries such as of insulin and cortisone, to the benefit of countless patients.

Hostile ridicule

The story has been told to generations of medical students, of how young George in February, 1891, age 25, presented his plan, at the Northumberland and Durham Medical Society, to treat a woman of 46 with myxoedema with injections of an extract of sheep's thyroid. He proposed getting the thyroids from an abattoir, dissecting them out under antiseptic conditions and then preparing a liquid extract. But at the meeting he was ridiculed. One member said it would be just as sensible to inject an emulsion of spinal cord to treat spinal cord disease and the medical college refused facilities. However, he pressed on and started treating his patient on 13 April 1891 with twice weekly injections and she dramatically improved. This was reported in the British Medical Journal and again the following year when he included three other treated patients.

Why had his idea been mocked? Probably because two years earlier, in 1889, the distinguished French physician and researcher, Charles Edouard Brown-Séquard, had reported what were regarded as disreputable experiments on rejuvenation, injecting himself with extracts of dog and guinea pig testicle. The sensational nature of these experiments antagonised 'respectable' doctors and blinded many to the principle of organ replacement therapy that was trying to shine through.

Dawning understanding

Murray’s achievement was built on the studies and observations of other doctors in preceding years, as is usual with medical discoveries, and they, too, deserve credit. The full story is, therefore, more complex and contains some very human ingredients: missed opportunity, ignorant prejudice - like the reaction to the rejuvenating experiments - jealousy, rivalry and even deception. With hindsight, the steps taken were in logical order, but at the time doctors struggled with the unknown. For what the thyroid did was a mystery. It seemed important, given its very generous blood supply. Some wondered if it acted as a kind of safety valve to prevent sudden rushes of blood to the brain; others that it was involved in voice production; still others that it produced a ‘peculiar fluid’ of unknown function. Then, between 1836 and 1877, five English doctors pointed the way.

In 1836, Thomas King, pathologist and surgeon at Guy’s Hospital, London, made a meticulous anatomical study of the thyroid and concluded that it did, indeed, secrete a peculiar fluid directly into the blood stream and that this fluid possibly contained ‘a particular material principle’ with important functions. The word ‘hormone’ was yet to be coined, but King is regarded by some as the ‘Father of Endocrinology’ for this conclusion. He also found abnormalities in the thyroid and related them to ‘peculiarities’ in the patients during life. Frustratingly, he provided no clinical details - a missed opportunity.

In 1850, Thomas Curling, surgeon at the London Hospital, found no trace of a thyroid at post-mortem in two patients with cretinism and concluded that this most probably had something to do with their condition.

In 1871, Hilton Fagge, a physician at Guy’s, described four cases of cretinism and argued that failure of thyroid function was to blame. He also accurately predicted the clinical picture were this to happen in adults. He did not have long to wait, for, in 1874, Sir William Gull, his senior physician colleague at Guy’s, reported five cases of what he called ‘A Cretinoid State supervening in Adult Life in Women’.

Finally, in 1877, William Ord, physician at St Thomas’ Hospital, London, coined the term ‘myxoedema’ for these adult patients, from the ‘mucous oedema’ which, at post-mortem in one patient, he considered underlay the skin. This was an inspired invention; a snappy-for-the-times, memorable, single-word label which persists to this day as the alternative name for hypothyroidism - underactivity of the thyroid. He also described the ‘practical annihilation’ of the thyroid at the autopsy, objective evidence, as he concluded, of a possible causal link to the condition. He proposed an engaging, if incorrect, theory to explain the lethargy, inertia and slow responses of the disease; that they might result from the sheathing and insulation of the body in a jelly-like, mucin-laden integument that interfered with sensory perception and stimulation. Maybe there is yet an element of truth in this.
**The Swiss key**

The next key studies were, fittingly, from two Swiss surgeons, Jacques-Louis Reverdin in Geneva and Emil Theodor Kocher in Bern. This was fitting because goitre was endemic in Switzerland and in other land-locked mountain valley regions across the world, due, as we now know, to iodine deficiency. We had our own ‘Derbyshire neck’. So extremely common was goitre in the Tyrol, that in 1775 a remark is recorded of an English visitor that he would have been handsome if only he had had one! These goitres could be huge and constrict the windpipe, and surgeons sometimes had little choice but to try to remove them despite the very high surgical mortality. With experience, however, an increasing number of patients survived the operation, which was often one of total thyroideectomy, the whole thyroid being removed. Reverdin and Kocher had become experts, especially Kocher who carried out over 4000 thyroideectomies in his career, with an ultimate operative mortality of under 0.5% by 1912, when it had previously been so high that in 1850 the French Academy of Medicine banned the operation! Mark you, the falling mortality will have had, in addition to ever-improving surgical techniques, something to do with ceasing to attempt a total excision, as we shall shortly see.

For, critically, Reverdin in 1882 reported long-term ill effects from surgically successful total thyroideectomy and realised that these effects looked just like the patients described by Gull and Ord. He proposed the term ‘myxoedème opératoire’ and substituted subtotal thyroideectomy for total, as he felt that complete loss of the thyroid was to blame. He spoke to Kocher who then investigated his post-operative patients and found the same. Strangely, however, Kocher at this point thought the problem was due to loss of the safety valve effect of the thyroid, the old theory, and to oxygen deficiency from post-operative narrowing of the trachea. Yet, he subsequently deceitfully promoted the priority of his findings and dismissed Reverdin’s contribution. In 1909 he became the first surgeon to receive the Nobel Prize for Medicine for his work on the thyroid. While there is no doubt of Kocher’s overall far far greater contribution to thyroideology than Reverdin’s, in the matter of operative myxoedema Reverdin holds the intellectual property. Some feel he should have shared in the Prize.

**The missing link**

The final piece in the jigsaw ultimately leading to Murray’s treatment plan came from a young German immigrant, working at St Thomas’ in throat disease. This was Felix Semon, later Sir Felix and doyen of British laryngology. In 1883 he proposed that myxoedema, cretinism and the effects of total thyroideectomy were all due to the same cause, absence or degeneration of the thyroid. He, too, was at first ridiculed, but the Clinical Society of London undertook to canvass 115 British and European surgeons for their experience of thyroideectomy - a remarkable project for its time - and their feedback squared with Reverdin’s and Kocher’s observations.

The reader may find it odd it should have taken so long to realise that total thyroideectomy was bad, but surgeons in those days seldom follow-up their patients once discharged from hospital. The fact that they had survived an operation was, alone, regarded as a success, but long-term complications were often missed.

**Treatment at last**

With all this evidence, another English surgeon and researcher, Victor Horsley, later Sir Victor and eminent neurosurgeon, advocated grafting sheep’s thyroid to treat myxoedema. Two Portuguese doctors, Antonia Maria Bettencourt-Rodrigues and José Antonio Serrano of Lisbon, then did this in 1890. They found an immediate improvement before the graft itself could have started working and concluded that this must be due to simple absorption of ‘juice’ from the grafted gland. This was a conclusion of extraordinary importance and set the stage for George Murray, who knew of this work, to prepare a thyroid extract and inject it. In fact, Bettencourt had beaten him to it in 1890, but found difficulty repeatedly preparing the extract, did not persevere and later in life acknowledged Murray’s pride of place in the discovery.

Murray and others quickly established the principles of treatment of myxoedema to which we still adhere, as large series of cases were quickly assembled. There was clearly no shortage of them as doctors everywhere realised in retrospect they had seen such cases. Considering the pretty uniform picture of overt hypothyroidism, it is rather remarkable the condition was not recognised sooner as a distinct clinical syndrome. Whole sheep thyroid or its extract, orally, replaced injections within months, the disgusting taste needing disguised in a sandwich, or lightly fried with anchovy paste on toast, or taken with current jelly. The beneficial effects seen were remarkable. As one physician put it:

‘This treatment is invariably followed by an improvement, by a rapid change in the appearance of the patient – there is a complete transformation, and the patient has ceased to be a patient, and appears a new individual’.

The miracle had occurred; clinical endocrinology was born.

This article was written by Dr Stefan D Slater, Retired consultant physician & endocrinologist MD(Hons) FRCP(Edin), FRCP(Glas), FRCP(Lond), FRCP(Ire)

For further information, go to www.jameslindlibrary.org/articles/the-discovery-of-thyroid-replacement-therapy/

**Cretinism** is a term used in the past for untreated congenital deficiency of thyroid hormone (congenital hypothyroidism) which causes severely stunted physical and mental growth. Since the inclusion of congenital hypothyroidism (CHT) in 1981 on the list of diseases tested on blood taken from the heel prick performed on babies when first born, this rare condition can thankfully now be quickly diagnosed and treated in the UK.
Bone and thyroid disorders

Thyroid hormones are essential for normal bone strength. Throughout our lives, the cells in bones break down and re-grow, a process known as remodelling. A proper balance of breaking down and rebuilding bone tissue is needed for bones to stay strong. As we age, bone tends to break down more quickly and rebuild more slowly. Hyperthyroidism (over-active thyroid) can accelerate bone breakdown and cause osteoporosis (fragile, porous bones). Hypothyroidism (under-active thyroid) can also impairs bone formation in children.

What is osteoporosis?

Osteoporosis - literally 'porous bones' - is a medical condition whereby your bones become fragile and are more likely to break. The common sites for breakage are the wrist, spine and hip. Although osteoporosis can be treated it is better to prevent it in the first place.

How does osteoporosis occur?

Two types of cells are constantly at work in your bones to allow your skeleton to grow and repair any damage such as fractures. 'Osteoclasts' break down the bone while 'osteoblasts' build it up again. Each 'turnover' cycle normally takes 200 days. Many factors influence this process of bone replacement, including hormones, the amount of exercise you take and the amount of vitamin D and calcium in your diet. The rate at which the bone replacement occurs is normally in balance. If more bone is lost than is replaced, your bones become less dense and you may develop osteoporosis. If you develop osteoporosis your bones can break more easily.

Who is at risk for osteoporosis?

All men and women are at risk for osteoporosis - everyone starts to lose some bone density from the age of 35 years and this is just a normal part of ageing. It is more common, however, in older women after the menopause, as they stop producing oestrogen, a hormone that protects the bones. After the menopause bone can be lost more rapidly over the next five to ten years.

Factors that increase the risk of osteoporotic fractures include:

- Personal history of a broken one, especially a fragility fracture either occurring spontaneously, or as a result of low trauma such as a minor fall
- Family history of osteoporosis or low trauma fracture
- Early menopause, previous steroid therapy
- Anorexia nervosa, low body weight, poor diet, smoking, excessive alcohol intake, lack of exercise or mobility
- Prolonged untreated hyperthyroidism,
- Prolonged over-treated hypothyroidism
- Other illnesses such as rheumatoid arthritis, coeliac disease, and primary hyperparathyroidism

What is the link between thyroid disease and osteoporosis?

Thyroid hormone affects the rate of bone replacement. Too much thyroid hormone (i.e. thyroxine) in your body speeds the rate at which bone is lost. If this happens too fast the osteoblasts may not be able to replace the bone loss quickly enough. If the thyroxine level in your body stays too high for a long period or the thyroid-stimulating hormone (TSH) level in your body stays too low for a long period then there is a higher risk of developing osteoporosis. There is also some evidence that people with low TSH levels may lose bone at a faster rate than those with normal TSH levels even when the blood thyroxine measurement is within the normal range, but this is still being studied.

Over-active thyroid (hyperthyroidism)

If you have hyperthyroidism, the first step is to treat the over-activity. Once the level of thyroid hormone in your body has been reduced to a normal level the rate of bone loss will no longer be so rapid and the bone strength may improve. Some people, however, will have persistent bone loss, with or without thyroid disease, and postmenopausal women are at particularly high risk of this. If you have had prolonged untreated hyperthyroidism and have other risk factors for osteoporosis and bone fractures, a bone mineral density scan two to three years after your thyroid treatment starts will help assess your risk. If a bone density scan shows osteoporosis then this can be treated with medication.

Under-active thyroid (hypothyroidism)

An under-active thyroid is not, in itself, a risk factor for osteoporosis, but if you are prescribed levothyroxine to increase your thyroid levels to the normal range you should have regular blood tests, at least once a year, to ensure your thyroid hormone levels are not too high.

How can I reduce my chance of osteoporosis?

You can help keep your bones healthy by eating a well-balanced diet containing calcium-rich foods, maintaining normal vitamin D levels, avoiding smoking, keeping your alcohol drinking to within recommended limits, and exercising regularly. High impact exercise, such as jogging or power walking, helps strengthen bones. Other exercises, such as Tai-Chi, may be useful in improving balance, therefore reducing the risk of falls which could break bones. Hormone Replacement Therapy (HRT) may help to reduce the risk of osteoporosis in women but it is now recommended only for the treatment of menopausal symptoms and may be associated with increased risk of other conditions depending on the individual. Spending 10-20 minutes every day in the sunshine provides the best source of vitamin D during summer months.

How much calcium should I take?

The National Osteoporosis Society (www.nos.org.uk) recommends a daily intake of 700mg of calcium for men and women, including pregnant women, or up to 1,000mg daily if you are on osteoporosis drug treatments. If you are breast-feeding you need to increase your calcium intake by an extra 550mg daily.

What foods contain calcium and vitamin D?

Calcium is most easily obtained from (preferably low-fat) dairy products such as milk, cheese and yoghurt. One pint of skimmed milk contains 680mg of calcium. Certain types of fish, and green vegetables such as okra and watercress, are also a good source of calcium if you dislike or cannot consume dairy products. Oily fish, such as salmon, trout, mackerel, herring (including kippers) and fresh tuna contain vitamin D. Even if you are taking other medication for osteoporosis if there is not enough calcium or vitamin D in your diet and/or your bone density is reduced then you should talk to your doctor about taking calcium and vitamin D supplements.

Future research

Much research is taking place on how to best manage bone conditions such as osteoporosis in thyroid patients. Joint winners of the 2007 BTF Research Award Professor Duncan Basset and Professor Graham Williams used the BTF award to study the role of a transporter of thyroid hormone called MCT8 and the role it plays in bone mass and skeletal development. They were able to show for the first time that active thyroid hormone transporters within the body such as MCT8 are essential for normal skeletal development and bone mass. This study has led to more extensive studies and attracted further funding.

Professor Bassett commented: 'We hope these studies will yield important new insights into the regulation of both skeletal development and adult bone turnover and provide the basis for new approaches to prevent bone loss in patients with elevated thyroid hormone levels.'
Research News

Go-ahead for new study targeting the causes of Graves’ disease

Apitope, a European biotech company focused on the discovery and development of revolutionary disease modifying therapies for autoimmune and allergic diseases, including Graves’ disease, have recently received regulatory approval from the Medicines & Healthcare Products Regulatory Agency for its Phase I study into Graves’ disease. The BTF will help provide advice and insight into clinical plans and during the clinical trials. Screening of patients for the study is planned to commence in June 2016 at the following specialist centres located in the UK: Royal Victoria Infirmary, Newcastle; Queen Elizabeth Hospital, Birmingham; University Hospital of Wales, Cardiff; The Christie, Manchester; King’s College Hospital, London.

Other centres will also be participating from other countries of the European Union.

Dr Keith Martin Chief Executive Officer at Apitope says: ‘These are very exciting times for Apitope and the Graves’ disease patient community. This will hopefully be the first study on a road that will lead us to the first potential new drug therapy for Graves’ disease in many years; it will be unique in that it is targeting the cause of the disease.’

Further information about this study and other Apitope development programmes can be found on the Apitope website www.apitope.com

New study into combined T4/T3 treatment

The BTF has been invited to join an independent advisory panel for a study on the development of a new formulation of thyroid hormones that would combine T4 with a sustained release formulation of T3. Diurnal Ltd and the University of Sheffield are applying to the EC for a grant to support the production of the drug, phase 1 clinical studies and a phase 2 proof of concept study. They believe they have the technology to test for the first time the effects of a truly normal physiological ratio of T3:T4 and hopefully improve quality of life for those patients who feel T4 alone does not provide full replacement. Results of the grant application will be known in October.

BTF Research Award findings may help pave the way for worldwide thyroid screening in pregnant women

Dr Peter Taylor, winner of the 2014 Research Award for his studies into the management of hyperthyroidism during pregnancy explains: ‘There is growing interest in the need for universal thyroid screening in pregnancy, with its recent introduction in China and likely introduction in Spain and India soon. Universal thyroid screening of pregnant women is also cost-effective and compares favourably to commonly screened for conditions such as gestational diabetes. Whilst all major endocrine, thyroid and obstetric societies recommend that clear cases of thyroid disease should be treated in pregnancy, we are currently unclear as to whether individuals with borderline thyroid abnormalities in pregnancy (subclinical hypothyroidism and isolated hypothyroxinemia) should also be treated.’

To an extent this can be addressed using the Controlled Antenatal Thyroid Study (CATS) obstetric outcomes that we are currently analysing which have shown some benefits in treating these borderline thyroid abnormalities. In particular, treatment has resulted in fewer premature babies and higher birth weights as well as reducing the number of early caesarean sections. Universal screening may also potentially reduce the number of stillbirths. Findings from this study and others may provide the necessary data to encourage universal thyroid screening.

Doris Godfrey Research Award 2016

Simon Pearce, Professor of Endocrinology and Honorary Consultant Endocrinologist, Institute of Genetic Medicine, International Centre for Life, Newcastle upon Tyne was awarded the 2016 BTF Research Award for his study: Differentiated thyroid cancer survival, recurrence rates by disease stage and quality of life in the Northern Cancer Network

Professor Pearce and Chief Investigator Dr Petros Perros, give a summary of the study:

Thyroid cancer causes about 2,500 deaths in the UK every year. International statistics show that the UK has a higher death rate compared to many other European countries. It is unclear why that might be the case; especially since a lot of NHS resources have been allocated to cancer care over the past 20 years. One possible explanation is that very small thyroid cancers (which rarely cause death) are not recorded in UK national statistics. This study will look at death statistics from thyroid cancer with relation to how advanced the cancer was when it was diagnosed. Such information will make it possible to compare with other countries in a more informative and fair way, so that we can understand why there are differences. This is important in planning and improving services for patients with thyroid cancer. Besides surviving from cancer, the quality of life of thyroid cancer patients is important. This study will also find out about quality of life of survivors of thyroid cancer five and 10 years after they have been diagnosed. Correlating quality of life measurements with other aspects of the cancer (for example how advanced it was when diagnosed and with some of the treatments) will give us a better understanding of how to treat patients with thyroid cancer in future.

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Bipolar disorder and thyroidectomy

N asks: I have a bipolar disorder. Now I have been diagnosed with thyroid cancer and it is proposed to remove my thyroid. Do you know if my mood might be affected by the lack of a thyroid?

Our medical adviser replies: Hypothyroidism can certainly cause significant depression but if s/he is on the appropriate levels of levothyroxine this shouldn’t be a problem.

For someone with a psychiatric background there is a good case for using recombinant human TSH, (a therapy that allows you to remain on levothyroxine throughout treatment) for radiiodine ablation or for diagnostic purposes rather than levothyroxine withdrawal, which may well precipitate more psychiatric problems. The 2014 BTA guideline recommendation on this subject is below, and you may wish to bring this to the attention of the doctors treating you if they plan radioiodine ablation with levothyroxine withdrawal.

For the groups of patients with the conditions listed above, recombinant human TSH is the only possible or safe option for diagnostic purposes and for ablation or therapy:

- hypopituitarism
- severe ischaemic heart disease
- previous history of psychiatric disturbance precipitated by hypothyroidism
- advanced disease/frailty.

Gap between taking levothyroxine and calcium products

M asks: I found the feature on thyroid and weight gain (BTF News 91, page 8) to be really helpful but have a query in relation to some advice that was published alongside it.

Within the section headed ‘Tips and advice on diet and thyroid’ the author identifies that calcium-rich foods can interfere with levothyroxine absorption, but there is a discrepancy within the article about the interval which should be left, suggesting both that there should be a ‘gap of four hours between the two’, and that levothyroxine is in fact best taken on an empty stomach at least half hour before food’. It is then stated that having left a thirty minute gap, lots of milk should be avoided.

The BNF (British National Formulary) states that levothyroxine should ‘preferably be taken at least 30 minutes before breakfast, caffeine containing liquids or other medication’.

I have previously been advised that a gap of four hours should be left between levothyroxine and calcium supplements which might be the gap alluded to in the article, but would be interested to know if there is clear evidence to avoid lots of milk for four hours after taking levothyroxine as is suggested, and if this is the case why the BNF is out of step? Lastly, if the advice in the article is correct, presumably reducing my breakfast milk will increase levothyroxine take-up? Since I only have annual bloods, how should this change be managed?

Our medical adviser replies: The published evidence on the topic derives mainly from two studies; One entitled Timing of levothyroxine administration affects serum thyrotropin concentration. Clinical Endocrinology Metabolism. 2009;94:3905-3912


www.ncbi.nlm.nih.gov/pubmed/21149757

The first study compared patients taking levothyroxine within 30 minutes of breakfast with taking levothyroxine four hours after the last meal of the day. Absorption of levothyroxine was better when taken four hours after the last meal. The second study showed that taking levothyroxine 60 minutes before breakfast on an empty stomach was better than taking it within two hours of the last meal of the day, which in turn was better than taking it within 20 minutes of breakfast. So, we can conclude that taking food may influence the absorption of levothyroxine for up to four hours and the closer together these are the greater the effect on levothyroxine absorption. Calcium salts have been reported to interfere with the absorption of levothyroxine (see Exaggerated levothyroxine malabsorption due to calcium carbonate supplementation in gastrointestinal disorders by Ann Pharmacother. 2001 Dec;35(12):1578-83) www.ncbi.nlm.nih.gov/pubmed/11793625.

I am not aware of any literature specifically implicating milk and dairy products, however it is likely that calcium in food products has similar effects to calcium tablets.

I hope this explains why the advice is not simple and may appear to be inconsistent! I would add that for most people taking levothyroxine the effects of timing on the control of the condition (hypothyroidism) are minor and of no clinical significance with the exception of pregnant women and patients with a previous history of thyroid cancer who are on suppressive levothyroxine treatment (where minor deviations of thyroid hormone levels may have important consequences). For patients who are established on levothyroxine treatment and whose biochemical control is satisfactory, there is no need to be concerned or change routine, if whatever you are doing is working for you.

Cholesterol and the thyroid

B asks: I’ve had an underactive thyroid for several years, I eat a healthy diet with no unhealthy fats, cakes etc. However, to my surprise I now have a cholesterol level of 6.7, but my doctor didn’t acknowledge my suggestion of a connection with my thyroid
issue/medications. As she knows I don’t drink, smoke and eat a plant whole food diet, she said it more likely inherited. Not so, plus I’d never had an issue with cholesterol prior to having my thyroid issue and I’m now 53. I have low blood pressure, so again not the norm if you have high cholesterol from diet or lifestyle.

So my question is, do you have any information that I can take to my doctor about this issue? For example is it helpful to up my levothyroxine a little or every second day, to see if that reduces cholesterol etc?

Fifty years of age is the average for the menopause, I’m not quite there yet, but obviously very likely to be in the process. If it’s not my thyroid, could it be the menopause causes a shift?

I’m not keen to start on statins at some point in the future, but as I already eat an oat bran, fruit, vegetable and bean diet, I know I can’t just stop eating or drinking something that is considered unhealthy or is high cholesterol. I wondered whether I could have my levothyroxine dose adjusted up slightly but as my results are within the normal range, I know my doctor won’t be keen to adjust my dose without a good argument to support the idea.

Any help you can give will be greatly received. From the above I’m obviously running with the idea my thyroid is to blame, but I am open to other ideas too, if I can see a connection. In many ways I wish it were because I eat unhealthily, was a smoker or drinker, as I could then just change my diet or lifestyle and thereby reduce my cholesterol naturally.

Our medical adviser replies:
Whilst untreated hypothyroidism may be associated with raised cholesterol, it is unlikely that adequately treated hypothyroidism with a normal serum TSH concentration is responsible here. Similarly it is unlikely that the menopause is causing this. It is excellent that you lead a healthy lifestyle with a healthy diet although a number of people who lead healthy lives have problems with raised cholesterol and require treatment with statins for this.

If there is scope to increase the dose of levothyroxine slightly then it would be OK to do this as long as serum TSH stays in the normal range. I do however feel it is unlikely that this will lower the serum cholesterol dramatically.

Thyroid eye disease referral and support

R asks: I was diagnosed with Graves’ disease around 15 months ago, which is being controlled. I still have pain around my right eye socket and occasional feeling of grittiness. My eyes also do not look the same in comparison to photos of when I was around 17. This has all been devastating and upsetting to me. I wonder if you have any information on the best treatment available to address the ‘sensation’ around the right eye (orbital) and how I can obtain orbital surgery to help to return my eyes to the way they were previously. Is there any way I can also be supported with this matter? My condition has really changed my life and I feel a lot more restricted now, so any support whatsoever would be marvellous.

Our medical adviser replies:
You should discuss with your GP or endocrinologist whether you have thyroid eye disease. If that is the case then referral to one of the multidisciplinary centres for treatment of thyroid eye disease on the NHS may be indicated. Recent national guidelines published by the Royal College of Physicians - Management of patients with Graves’ orbitopathy: initial assessment, management outside specialised centres and referral pathways. www.clinmed.rcpjournals.org/content/15/2/173.full.pdf+html (Clinical Medicine 2015;15:173-8) recommend that GPs or endocrinologists should refer patients whose dominant clinical features are due to thyroid eye disease to specialised ophthalmology units or joint thyroid eye clinics. The precise type of treatment most appropriate will depend on the assessment at the specialised clinic and may include orbital decompression.

The BTF has a list of telephone volunteers for members to call for support (see the back page of this newsletter) that you may find helpful. You can also join the BTF closed Facebook group for people with hyperthyroidism which many people find to be a useful source of support.

Congenital hypothyroidism and IQ

M asks: I have read a page on your website regarding congenital hypothyroidism (CHT) and newborn babies www.btf-thyroid.org/information/leaflets/42-congenital-hypothyroidism-guide Regarding CHT patients it has been written ‘Screening for CHT at birth and starting treatment if the test is positive means that a low IQ and other development problems can be avoided.’ However I have seen some scientific articles, which are investigating IQ scales in children with CHT (even with early treatment) and normal children in a long-term and short-term period, which suggest CHT children, would have a lower IQ in comparison with normal children. I am wondering about the contradiction between the correctness of the facts on the BTF website, as a scientific approved website, and those articles. My child is a 16 days old girl with positive CHT and I found these different texts regarding this issue confusing. I do appreciate if you could help or address this contradiction on your website.

Our medical adviser replies:
The outlook for babies with CHT who are treated early is excellent which is why we screen for this condition.

Babies with severe CHT may (in the literature) have subtle differences when compared to children without CHT as you suggest (some but not all studies) - but they still attend normal school and are unlikely to require special needs input etc. Some of the suboptimal outcome data may also reflect suboptimal management in childhood of course. Babies born now are managed better than babies born in the past (started on levothyroxine more quickly, reviewed more frequently etc).

It is worth reflecting on the fact that whether you are born into a loving, caring, supportive environment matters much more….and a lower IQ (by even a few points) does not mean an abnormal IQ.

Hence I think the statement ‘Your child has an excellent chance of a normal childhood, going to a normal school and living a normal independent life as an adult’ is undoubtedly correct - I know because I see it all the time! The literature is confusing though - as you have discovered.

How lucky we are to live in countries where screening for CHT takes place…it is not so in many parts of the world.
Leaving a legacy to the BTF

Help to make a real difference by remembering BTF in your Will. Any gift, large or small, makes a real difference. Legacy donations allow us to continue providing life-changing support to people with thyroid disorders.

If you do decide to remember BTF in your Will, your gift will mean that BTF will still be here for people who need our support in years to come. By leaving a legacy you can take advantage of the reduced rate of inheritance tax of 36% (previously 40%) that came into effect from April 2012 for estates leaving a legacy to charity. Call 01423 810093 or email legacies@btf-thyroid.org for an information pack.

Shop online and raise money!

easyfundraising.org.uk

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

So how does it work?

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

How much can you raise?

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

Save money too!

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

JustTextGiving from Vodafone

You can support people with thyroid disorders by donating via your mobile phone. Just text THYR01 and the amount you would like to donate to 70070.

Unity Lottery

Play the Unity Lottery and win up to £25,000 and many more prizes every week!

Directly supporting the British Thyroid Foundation, Unity is a lottery with a difference. We receive profits directly from the number of lottery players we recruit, so we need your support. For every £1 entry, 50p comes directly to the BTF as profit.

Directly support the BTF by playing the Unity lottery and be in with the chance of winning £25,000!

How it works

For just £1 per week you will be allocated a six digit Unity lottery number. You can purchase more than one entry if you wish. Every Saturday, the lucky winners are selected at random and the prize cheques issued and posted directly to you, so there is no need for you to claim. You must be 16 over to enter. Winners have to match 3,4,5 or all 6 digits of the winning number in the correct place in the sequence.

To join go to: www.btf-thyroid.org/support-us/3-play-the-btf-lottery

PRIZES

£25,000
6 digits

£1000
5 digits

£25
4 digits

£5
3 digits
Local Groups

Below is a list of official BTF Local Groups with details of their meetings:

Birmingham

Next meeting: TBC
Location: Yardley Baptist Church, Rowlands Road, South Yardley, B26 1AT, off the A45 Coventry Road. Free parking available.
Programme: Patient Group, Information and Support Meeting Head & Neck Disease (including the thyroid).
Donation: £2 voluntary donation.
Contact: Janet Tel: 0121 628 7435 or email: janetdp@googlemail.com

Cambridge

Next meeting: Saturday 12 November 2016 10am-1pm (provisional).
Location: Weston Colville Reading Room CB21 5NX
Programme: Check the BTF for details. Tea, coffee and biscuits provided.
Donation: Suggested minimum donation: £4 to cover costs.
Contact: Mary on 01223 290263 or email butterflyecho@hotmail.com
Please call or email if you are thinking of attending the meeting to give us an idea of numbers.

Edinburgh

Next meeting: The Edinburgh BTF Support Group meets on the last Tuesday of the month except for school holidays. Check the BTF website for further details.
Location: Liberton High School, Gilmerton Road, Edinburgh, EH17 7PT.
Contact: Margaret Tel: 0131 664 7223 or email: M2mcgregor@aol.com

Leeds (Wharfedale)

Next meeting: Caroline is currently confirming details of her next meeting. See the BTF website for more details.
Contact: Caroline on 0113 288 6393 or email: cfields237@btinternet.com

London

Next meeting: See the BTF website for more details.
Location: Crown Court Church, Russell Street, Covent Garden, London WC2B 5EZ
Programme: TBA
Donation: Suggested min donation £3.
Contact: Denise denisesims@btf-thyroid.org

Milton Keynes

Next meeting: Saturday 8 October 2016
Location: The Pavilion, Open University, Milton Keynes, MK7 6AA.
Programme: Patient’s experiences - see the BTF website for details.
Donation: £2 voluntary donation.
Contact: Wilma Tel: 01908 330290 or see www.thyroidmk.co.uk or find us on Facebook.

Milton Keynes welcomed Dr Mark Vanderpump to their group meeting in June. He gave a talk to a packed room on the management of hypothyroidism and its challenges.

Are you interested in bringing people together to start a BTF support group in your area? We would particularly like to set up new groups in the North East, North West, Bristol/Bath area and Wales. Guidance and support from BTF HQ is available.

Buy a teddy and support the BTF

Buy one of these adorable teddies for £7.50 and all the profit will go towards the BTF. Go to the BTF website to order online or by cheque by downloading and sending with the order form on the website.

Milton Keynes local BTF Group raised a fantastic £270 from tokens collected at their local Waitrose in the Green Community Token scheme they took part in earlier this year.

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### BTF LOCAL COORDINATORS

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

| Birmingham | Janet (PC,CS,RAI,PH) | 0121 6287435 |
| Cambridge  | Mary (O,RI,U)        | 01223 290263 |
| Edinburgh  | Margaret (PC)        | 0131 6647223 |
| Leeds      | (Wharfedale) Caroline (O,U) | 01132 886393 |
| London     | Denise (U)           | denisesims@btf-thyroid.org |
| Milton     | Keynes Wilma (U)     | 01908 330290 |

### BTF TELEPHONE SUPPORT CONTACTS

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

| Dave         | 07939 236313 |
| Jackie (PC,CS)| 01344 621836 |
| Gay (G,TS)   | 020 8735 9966 |
| Karen (U)    | 01628 529212 |
| Wilma (U)    | 01592 754688 |
| Angela (U)   | 01943 873427 |
| Maria (U)    | 020 87934360 |
| Ursula (U)   | 07720 659849 |
| Colin (O,RI,U)| 07973 861225 |
| Olwen (O,RI,U)| 01536 513748 |
| Jane (GR,RI,TED,G,U)| 01737 352536 |
| Peter (TED,GR)| 01200 429145 |
| Penny (Ch)   | 01225 421348 |

**KEY**

- **6 - 8pm weekdays**
- **2 to 5pm Monday, Tuesday and Thursday**
- **After 6pm weekdays and anytime weekends**
- **10am to 2pm weekdays**
- **Up to 8pm**

Please note: both local and telephone coordinators are volunteers and although they will make every effort to be available at the times published this cannot always be guaranteed.

### OUR PARTNER ORGANISATIONS

- **AMEND** The Association for Multiple Endocrine Neoplasia Disorders
  Tel: 01892 518076  [www.amend.org.uk](http://www.amend.org.uk)
- **Hypopara UK** Helpline: 01342 316315  [www.hypopara.org.uk](http://www.hypopara.org.uk)
- **Thyroid Cancer Support Group Wales** Tel: 08450 092737  [www.thyroidsupportwales.co.uk](http://www.thyroidsupportwales.co.uk)
- **Thyroid Cancer Support Group Ireland**  [www.thyroidcancersupport.ie](http://www.thyroidcancersupport.ie)
  email info@thyroidcancersupport.ie
- **Butterfly Thyroid Cancer Trust** Tel: 01207 545469  [www.butterfly.org.uk](http://www.butterfly.org.uk)
- **Cancer52**  [www.cancer52.org.uk](http://www.cancer52.org.uk)
- **Thyroid Eye Disease Charitable Trust** Tel: 07469 921782  [www.tedct.org.uk](http://www.tedct.org.uk)
- **British Thyroid Association**  [www.british-thyroid-association.org](http://www.british-thyroid-association.org)
- **British Association of Endocrine and Thyroid Surgeons**  [www.baets.org.uk](http://www.baets.org.uk)

### CURRENT MEMBERSHIP RATES

<table>
<thead>
<tr>
<th>Members living in the UK</th>
<th>By cheque</th>
<th>By standing order</th>
<th>Lifetime membership £200 by cheque</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full: £20 per year</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concession: £10 per year</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Members living overseas</th>
<th>By cheque from a UK bank account</th>
<th>By standing order through a UK Bank</th>
<th>By sterling bank draft drawn on a UK Bank</th>
</tr>
</thead>
<tbody>
<tr>
<td>£25 Europe</td>
<td></td>
<td></td>
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</tbody>
</table>

Concession: unwaged and children under 18. Please help us by ensuring that you pay the correct subscription.