A lasting legacy

At the end of 2014 we were delighted to receive the news that BTF had been left a legacy of £48,000 from Doris Godfrey, who suffered from hyperthyroidism. Her generous support will fund two BTF Research Award Grants. The first will be awarded in 2016 and will be named the BTF Doris Godfrey Research Award.

We contacted her nephew, Ashley Godfrey who kindly provided us with this heart-warming account of her life dedicated to looking after others:

Doris was born in 1923 in Foulridge in Lancashire. Later, the family moved to live in Rothwell, near Leeds, where Doris lived most of her life. She died in December 2013 aged 90 years.

In her early teens Doris wanted to train as a nurse. Her opportunity came and she started her training at Pinderfields Hospital in Wakefield. She excelled in her training and was proud of achieving the highest results in her group. She applied to become a nursing trainee at St James’s Hospital in Leeds which normally only accepted trainees who had matriculated but Doris was accepted because she had done so well at Pinderfields. Doris completed her training at St James’s and stayed at the hospital for the rest of her career.

Doris became the Sister of the Children’s Surgical Ward at St James’s. All the consultants who visited the ward knew Doris and held her in the highest regard. The children on the ward loved Doris because she provided them with the reassurance and kindness they needed.

When she wasn’t at work, Doris spent time caring for her mother, Edith, who suffered from Graves’ disease. Never a well person, Edith died in 1955 aged 66.

Doris never married and she continued to dedicate herself to nursing sick children until 1969 when she retired. At about this time she began to experience similar symptoms to her mother and was subsequently diagnosed with hyperthyroidism and, like her mother, underwent surgery to remove part of her thyroid gland.

The impact of thyroid disease on Doris and particularly her mother motivated her to arrange for a legacy to fund the work of the BTF and the British Thyroid Association in providing support for those with thyroid disease. She would have been thrilled to learn that her bequest will be used to support medical research projects that will benefit sufferers in the future.

It is thanks to the generous gifts from members and other supporters that BTF is able to continue the important work it does. Legacy donations, in particular, make a huge difference. Did you know, for example, that gifts in wills have made up almost 40% of BTF’s income during the last 12 months? If you would like to find out how you can support the BTF in this way please contact us for further information or go to our website for details (www.btf-thyroid.org/index.php/donate/legacy-giving).

Legacies to charity are free from inheritance tax – which may significantly reduce or eliminate the tax burden on your estate.
Dr Peter Taylor, Dr Mark Vanderpump

Professor Simon Pearce, Dr Petros Perros, Professor B Hickey

Miss Adler, Vivienne Rivis, Fiona Maxwell

Clerical Assistant: Helen Dawson

Head Office Volunteers: Jan Ainscough, Angela Hammond, Vivienne Rivis, Fiona Maxwell

Design & Artwork: Keen Graphics 01423 563888

Next issue of BTF News: June 2015

Happy New Year to all our members and thank you for all our lovely Christmas cards.

Obituary

Davinder Kaur Babraa, a former BTF trustee and local coordinator, sadly passed away after an illness on 20 November 2014 at the age of 77.

Davinder was a staunch supporter of the BTF and set up a very successful local BTF group in Plumstead in 1998, which frequently attracted around 200 people to meetings. She ran the group with the help of her husband, Gajinder, and friends, until health problems led her to step down in 2009. Via the telephone and the local BTF group she supported many hundreds of people, particularly offering her services to the Asian community.

Davinder was a trustee from 2001 to 2009, and actively engaged in meetings, clearly wanting to move things forward for people with thyroid disorders. Over the years she represented the BTF at a wide range of conferences, meetings and events in the London area.

Janis Hickey writes: ‘Davinder was always keen to get involved and help out. I remember the London Marathon in 2002. Davinder and Gajinder were there with us from BTF HQ, amongst the crowds, supporting our runners and handing out information about the BTF.

‘On another occasion I met with Davinder in Leicester in 2004 to take part in an interview for the ‘BG Show’ on Sky TV. The show was screened nationally - Davinder had written in to inform them of the work of the BTF and had been invited to appear. She knew it would be a good opportunity to raise awareness about thyroid disorders.’

Welcome to...

Our new patron Professor John Lazarus.

Professor Lazarus has been associated with the Cardiff Medical School for 42 years. During this time he has provided the clinical thyroid service in addition to performing thyroid-related research and was also much involved in undergraduate and postgraduate teaching.

Throughout his research career he has contributed many papers on iodine and iodide metabolism and thyroid hormone action on mitochondria. Together with the late Professor Reginald Hall a research programme documenting the clinical, immunological and psychological aspects of postpartum thyroiditis (PPT) was undertaken. Leading on from this work he then helped to conduct the first randomised controlled trial evaluating screening for thyroid function in early pregnancy. He has more than 240 PubMed publications as well as more than 20 book chapters and other papers accredited to him.

He has been associated with the BTF for more than 20 years and served as a trustee for nine years. He has also been a strong supporter of the European Thyroid Association being secretary-treasurer from 1996 to 2002. In addition he is a past president of the British Thyroid Association and also was the treasurer of The Association for the Study of Medical Education in the UK. He is a founder member of the European Group on Graves’ Orbitopathy. He is currently regional coordinator West and Central Europe for the Iodine Global Network.

Our new trustees...

Dr Tim Cheetham

Dr Cheetham is a paediatrician and paediatric endocrinologist who has a major interest in thyroid disorders in children. He sees children with congenital hypothyroidism (CHT) and children with acquired (usually autoimmune)
hypothyroidism regularly in clinic. He also manages children with thyroid gland overactivity (usually Graves’ disease).

Dr Cheetham is involved in the national screening programme for CHT as well as a number of studies that are looking at thyroid disorders in the young. He has provided advice to many families in recent years via his involvement with the BTF and hopes to make a useful contribution to the BTF in the years ahead as a trustee.

Carole Ingham

Carole Ingham is a former trustee, Chair of the trustee board and local co-ordinator from 1999 to 2013. Since resigning as local co-ordinator for the Bolton group she has continued to be a BTF telephone contact and member of the BTF thyroid cancer group and has represented BTF at many meetings and conferences over the years. Carole was diagnosed with follicular thyroid cancer in 1993 and was treated by a partial thyroidectomy and RAI ablation.

Carole retired from her job as residential support worker with people with learning disabilities after 29 years last year and now volunteers in the office and as bar co-ordinator for weddings, parties etc. at her village community centre. In addition to this she is also an organiser for her village annual flower festival which has generously supported BTF in the past.

Farewell to...

Professor Peter Hindmarsh whose term of office as a BTF trustee has now ended. Professor Hindmarsh has been a trustee since 2009 and is a consultant paediatric endocrinologist at Great Ormond Street, London.

The Big Give results

Thanks to all the supporters, trustees and patrons who took part in The Big Give Christmas Challenge in December. Over £4200 was donated which enables us to print and distribute the newly reviewed and updated information leaflets.
Innovative national thyroid cancer nursing posts

Two nursing posts have been established to support thyroid cancer sufferers.

A national survey conducted by Thyroid Cancer Forum-UK (TCF-UK) led by Dr Laura Moss, Consultant Clinical Oncologist, Velindre Cancer Centre, Cardiff demonstrated a wide variation in access to clinical nurse specialist (CNS) support for thyroid cancer patients. Patients in some geographical areas had no access whilst others were referred to CNSs specialising in other clinical areas. A proposal was therefore submitted to Macmillan for a national thyroid cancer CNS utilising a new model of working: the post holder having both a local clinical case load plus providing telephone support for patients across the UK in areas without thyroid cancer CNS access. The project was developed over a three year period and in January 2014 Ingrid Haupt-Schott was appointed to the post of Macmillan National Thyroid Cancer CNS. She is based at the Velindre Cancer Centre in Cardiff and works with three pilot centres (Glasgow, Norwich and Oxford). This service includes giving emotional and practical support as well as facilitating referrals to local services as required for newly diagnosed patients and for those who experience complications or difficulties in their cancer journey.

Another aspect of the role is networking with existing thyroid cancer CNSs and CNSs of other specialties caring for thyroid cancer patients, multidisciplinary teams (MDTs) and thyroid cancer patient support groups to facilitate individual patients' management as well as research, data collection and the potential for international collaboration.

In January 2015, a second post was launched. Geraldine Hamilton has been appointed as the Macmillan Thyroid Cancer Information Nurse Specialist to work on Macmillan’s national support line.

Geraldine is based in Glasgow and will be available to take calls and emails on a Monday and Tuesday morning, Wednesday afternoon and Thursday evening. The service is open to patients, friends, relatives and other health care professionals. She can be contacted on 0808 808 0000.

The two national Macmillan post holders are in the process of developing CPD (Continuing Professional Development) modules and potentially other educational material to improve the knowledge base of a broad range of nursing and allied health care professionals across the UK.

Dr Moss said ‘These projects will increase UK patients’ access to a thyroid cancer specific CNS and will improve the provision of information and support for patients and their families’.

Shop online and raise money!

Have you heard about easyfundraising yet? It’s the easiest way to help raise money for the British Thyroid Foundation! 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’s 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.

Sign up at http://www.easyfundraising.org.uk/causes/btf and start making a difference…simply by shopping. Thanks!
that a policy statement had been developed greater than 290µg/day. The supplement is 150µg iodine per day which is by The American Academy of Pediatrics in that appeared in the August edition of a talk summarised the findings of a short survey BTF prepared and published last year that asked for parents’ experiences of their child’s congenital hypothyroidism (CHT). Following on from the talk we have had enquiries from other hospital teams around the UK who have been interested in the work we do.

We have also been invited to talk at an upcoming educational meeting organised by the biopharmaceutical company Merck Serono. The meeting is entitled ‘Insights for Growth’ and is for endocrine nurses.

Thank you to all the parents who contacted us to let us know about their experiences and who have suggestions about how their child’s care could be improved. We would like to collate this information into an information guide for newly diagnosed families.

Iodine

Professor John Lazarus writes: I am pleased to report that The UK Iodine Group has recruited two new members, Mr Michael Marsh, Consultant Obstetrician at King’s College Hospital London and Dr Emilie Combet, Nutrition Scientist from Glasgow University. I would like to welcome them both.

I would like to draw attention to two articles that appeared in the August edition of IDD newsletter vol 42, no 3 2014. The first noted that a policy statement had been developed by The American Academy of Pediatrics in which a recommendation for iodine supplementation was made in relation to breast feeding mothers http://pediatrics.aappublications.org/content/133/6/1163.full.html. The suggested supplement is 150µg iodine per day which is intended to achieve an iodine intake of greater than 290µg/day. The recommendation also supported measures to reduce infant exposure to nitrates, perchlorate and thiocyanate, all of which are known to affect thyroid function especially in the neonate.

The second article emphasised these recommendations in an interview with Professor Heather Brumberg, a member of the American Association of Pediatrics Council on Environmental Health (http://www.medscape.com/viewarticle/829448#1). She commented that iodine deficiency is occurring in about one third of pregnant women in USA and that in her opinion, it would be difficult to get all the necessary iodine through diet alone. [Note that in the UK around two thirds of pregnant women are iodine deficient.] The iodine should be given as a constituent of a prenatal vitamin. The implications for UK and Europe are clear.

Thyroid eye disease

TEAMeD (Thyroid Eye Disease Amsterdam Declaration Implementation Group UK) of which the BTF is a member, has had the findings of a pilot study to assess the use of an office tool (DiaGO) developed to help early diagnosis of Graves’ orbitopathy (GO), published in the prestigious Journal of Clinical Endocrinology and Metabolism (J Clin Endocrinol Metab. 2014 Dec 8;jc20143146.)

The 20 point assessment tool was devised and tested on 104 Graves’ disease (GD) patients in two centres over 17 months: 77 attending endocrine clinics with GD and 27 ‘positive controls’ (ie those who were known to have GO) attending multidisciplinary thyroid eye clinics.

Those scoring positively in endocrine clinics were referred for ophthalmic assessment. Both the appropriateness of the referral and subsequent treatment were assessed. The study found that compared with the previous 17 months, there was a 36% increase in the number of referrals to the multidisciplinary thyroid eye clinics in Newcastle and Exeter in the time period in which the tool was in use, directly attributable to use of the tool.

The tool, which is sensitive to the diagnosis of GO, does not require specialist skills in ophthalmic assessment but can quickly and easily be used for assessment of all GD patients in any setting. In Newcastle, the tool significantly increased referral rates. Overall, half of those referred following use of this tool were offered specific treatment, suggesting its use might actively alter management of patients who might not otherwise have been referred to specialist ophthalmic care.

Thyroid cancer

The thyroid cancer group met in November 2014 to review progress.

The travel health insurance document is complete and is on the BTF website www.btf-thyroid.org/index.php/campaigns/thyroid-cancer/travel-and-travel-insurance

Many thanks to Carole Ingham for coordinating this project.

Judith Taylor recently coordinated submissions on behalf of the group to the All Wales Medicines Strategy Group (AWMSG) and the Scottish Medicines Consortium (SMC) in support of providing a new drug, cabozantinib, to patients with progressive medullary thyroid cancer. This drug offers hope to this small group of patients for whom there is presently no other treatment, by improving their progression-free survival and by relieving them of the debilitating diarrhoea which is a feature of advanced stages of this disease. It is already provided in England under the terms of the NHS England Cancer Drugs Fund. The submissions were reviewed beforehand by the thyroid cancer group and BTF medical advisors.

We made a submission to the AWMSG earlier in the year on behalf of vandetanib, which is also used in the treatment of progressive medullary thyroid cancer. Unfortunately we have now been informed that this has been declined, which means that the medicine in question will not be routinely available in the NHS across Wales for this condition.

We are waiting to hear the results of the Welsh and Scottish reviews of cabozantinib.

Work continues on revising the thyroid cancer booklet, and a FAQ/briefing about tyrosine kinase inhibitors.

Correction:
In BTF News 87 we mentioned a potential new drug to treat thyroid cancer called levantibin, This was spelt incorrectly, the correct spelling is lenvatinib.

Hypothyroidism

The group is continuing to bring together patient feedback and concerns and to work with our medical advisers to help to clarify, refine and communicate key messages for hypo patients and GPs.
importance of looking at patients as individuals and not taking the attitude that one type of treatment fits all. A talk by Dr Anita Boelen, oncologist at the Royal Amsterdam, is available, along with other resources, on the BTF stand. Mr John Watkinson (ENT Surgeon, Queen Elizabeth UHB) agreed to offer his and the services of a multidisciplinary team to help review the booklet. Kate Newbold and Alison Waghorn (General Consultant Surgeon at the Royal Liverpool Hospitals, organiser of BAETS 2014 and former BTF trustee) also expressed an interest in helping.

Whilst at the meeting the BTF also wanted to find out more about the ‘Differentiated Thyroid Cancer – Alert Cards’ produced by the Butterfly Thyroid Cancer Trust. Kate Farnell (founder of the charity) was a speaker at the meeting and answered our question by explaining how easy it was for clinicians to obtain the cards. Upon receipt of the hospital logo Butterfly arranges for it to be printed on the cards and the cards are sent back to the clinicians for distribution to the patients. The cards have helped many people to ensure they are prescribed the correct treatment for differentiated thyroid cancer.

Following this year’s successful meeting the BTF has been invited to the 2015 and 2016 meetings.

Janet and Carole would like to thank BAETS for a very informative and enjoyable event.

**British Thyroid Association meeting**

For several years the British Thyroid Association (BTA) has combined a training day with its annual meeting. BTF Director, Janis Hickey, attended the training day at St Thomas’ Hospital, London on 1 December 2014 during which Young Scientists and Clinical Specialist Registrars (SpR) enjoyed presentations given by experts from the UK and overseas about their work, bringing them up-to-date with important areas of thyroid disease research and management, followed by engaging discussions. Topics covered in the Young Scientists programme included a lecture on how to measure thyroid function and hormone action in humans and rodents (Dr Anita Boelen, Amsterdam) and a talk by BTF Trustee Dr Tim Cheetham (Newcastle) on the management of thyrotoxicosis in adolescence, followed by a presentation on challenging cases of thyroid disease management given by Professor Leonidas Duntas (Athens) and BTF Trustee Dr Mark Vanderpump (London).

The 63rd BTA Annual Meeting took place at St Thomas’ on the following day, attended by BTA members and other thyroid specialists. A symposium on paediatric and transitional dysthyroid disease was held in the morning session and included speakers Dr Tim Cheetham and Professor Peter Hindmarsh (London), both of whom work closely with the BTF helping to support parents and children. Professor Reed Larsen delivered the George Murray lecture (George Murray is universally recognised as the physician who in 1891 discovered that injections of sheep thyroid extract could be used to treat myxoedema.) – see ‘A history of the thyroid’ on page 8.

The afternoon’s oral presentations detailed some of the latest thyroid research taking place, with the prize being awarded jointly to Dr Peter Taylor (Cardiff) and Dr John Logan (London) for presentations on ‘Thyroid function monitoring and TSH levels in pregnant individuals on levothyroxine in the UK’ and ‘Thyroid hormones stimulate osteoclastogenesis via TRα-dependent actions in osteoblasts’, respectively. The BTF 2012 Research Award holder, Dr Vicki Smith (Birmingham) presented the results of her work on ‘Characterisation of thyroid structure and function in the PBF knockout mouse’ (for a full report see www.btf-thyroid.org/index.php/awards/research-awards/past-awards/2012-research-winner). Several studies had received support from the BTF, and this was gratefully acknowledged by the researchers.

Janis Hickey had the opportunity to inform attendees about the BTF’s work and developing role since 1991. She talked about current campaigns, contributions to research work, and the relationships with patients and physicians, highlighting the importance of continuing this work, despite the growing challenges of sustainability in the voluntary sector.

The BTF would like to thank the BTA for the invitation to attend the two-day meeting and for its interest in working together for the benefit of patients.

**National Institute for Health Research (NIHR) Clinical Research Network meeting**

The BTF was invited to take part in a meeting of the National Institute for Health Research (NIHR) Clinical Research Network as part of the Metabolic and Endocrine Disorders Speciality Group. The aim of the group is to develop, promote and support research into the speciality and to enable this they are keen for public and patient involvement by engaging with patient groups. BTF is already accredited as an NIHR partner which means that winners of the BTF Research Award are eligible to apply for access to additional NIHR funds to carry out their project.
If you are involved in a fundraising event in aid of BTF please get in touch so that we can send you sponsorship forms, posters and other publicity materials. We can also supply BTF t-shirts or running vests, but please allow enough time for us to get the right size for you.

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

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

Michael Knowles (pictured) raised over £300 for the BTF by taking part in ‘Movember’ (growing a moustache for the whole of November). His wife Lesley-Anne has an under-active thyroid.

Katrina Rutherford raised nearly £150 by completing four incredible challenges in Shanghai. She climbed Mount Huangshan (pictured), climbed the Shanghai World Financial Center, ran the Yangpu 8K run and finally the 2014 Shanghai Half Marathon in December.

One of our members, Sarah Carr, decorated a Christmas tree in her local church - St Mary’s Church, Alverstoke, Gosport as part of a sponsored Christmas tree festival. Sarah and her family decorated the tree with lots of gold and silver thyroids and also left information about the BTF for people to take at the bottom of the tree. Sarah’s daughter Cicely, who has hypothyroidism, is pictured here.

Rachael Senior has raised a fantastic £700 for the BTF by completing the Ipswich Half Marathon in September. She tells us the reason she decided to take on this challenge:

‘In 2013 my eldest brother was diagnosed with thyroid cancer and my dad was then diagnosed with prostate cancer.

‘After such a deflating year for our family I decided to make 2014 a positive one. I wanted to raise some money for a charity by doing something so outrageous for me that it would make people think they mis-heard. So in January I decided that I, Rachael Senior, the overweight, unfit, procrastinating, lazy, alcohol- and junk food-guzzling, vast slug that I am would take part in the Ipswich Half Marathon in September and I would raise money for two big causes close to my heart - the BTF and East Suffolk Prostate Support Group.

‘I spent the next nine months going out on runs twice a week, sometimes by myself but towards the end with my training buddy Scott who also took part in the half marathon with me.

‘The race day came and all were amused that my running number was 118 - so out came the emergency moustaches! I finished in two hours 53 minutes and 12 seconds just wanting to cry with relief that it was over. It was easily the hardest thing I have physically had to do.

‘But the important thing was I did it. Nine months beforehand I ran less than a half a mile with stops in between and I didn’t feel like there was enough oxygen in the world to save me, and yet here I was completing 13.1 miles in under three hours!’

Future fundraisers

Two runners are taking part in the Virgin London Marathon in April. They are Lauren Mitchell and Tina Jackson.

Tina says: ‘This will be my first and only time I will be running the marathon as it is something I have always wanted to do. My sister was diagnosed with thyroid cancer at the age of 37 and had to have her thyroid removed and undergo radiation treatment. She has thankfully now been given the all clear’.

www.justgiving.com/lauren-mitchell2
www.justgiving.com/tina-jackson5

Lucinda Witney, who suffers from hypothyroidism and accompanying weight struggles has decided to raising money to get to a healthy weight of nine stone by May 31 2015. Lucinda says ‘I will document my starting weight (God help me!) and update regularly to show (hopefully) progress.

www.justgiving.com/Lucinda-Witney

Steve Robb, who has committed to raise money for the BTF until his daughter who has congenital hypothyroidism is 18, is taking on several more running challenges this year including the Forfar Multi Terrain Half Marathon and the HOKA Highland Fling Ultra Marathon (53 mile trail run).

www.justgiving.com/errolrunner

Greg Bolt is taking part in the Southamton Marathon in April 2015.

www.justgiving.com/MrBolt

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.

£338 was received in memory of Mrs Moya Allen.

£75 was forwarded to the BTF from an individual who participated in a research study for Brunswick Insight in return for a charity donation.

Ms Searles and Ms Squires donated £500 to the BTF following treatment at the Royal Liverpool University Hospital.
A history of the thyroid

By W Michael G Tunbridge
Emeritus Physician, Nuffield Department of Medicine, Oxford, Dec 2014

Early discoveries

A swelling in the centre of the neck has been depicted in drawings and paintings, usually of women, since ancient times. The Chinese in 1600BC used burnt sponge and seaweed for the treatment of goitre but the precise anatomy of the gland was little understood until the 16th Century AD.

Even the name Thyroid was not coined until the 17C by Whaton who described the gland and in the 18C Haller included the thyroid among a group of glands without ducts pouring their fluids into the circulation and used the word struma for a swelling in the neck due to an enlarged thyroid.

The functions of the thyroid were barely understood until the 19th and 20th centuries. There were nevertheless important observations made during earlier periods which contributed to the gradual understanding of the importance of the thyroid for general wellbeing as well as the specific disorders of thyroid function which are well recognised today. In ancient India about 1400BC the separate location of the thyroid amongst other glands in the neck was understood and described as painful (as in acute thyroiditis or infection) or painless (as in benign nodular goitre). In ancient Greece Hippocrates around 400BC recognised goitre as a deformity but failed to distinguish it from other glands in the neck. The swellings were attributed to drinking snow waters. This was the era of ‘humours’ or spirits and the elements of earth, air, fire and water. In Roman times between 30BC and 50AD Celsus defined bronchocoele, a tumour of the neck thought to connect to the windpipe. He described cystic goitre and its surgery to relieve pressure. Pliny and others also referred to epidemics of goitre in the Alps and mentioned burnt seaweed. Galen in the second century AD in Persia described two glands that lacked ducts but ascribed to them the function of lubricating the voice box or larynx. Persian physicians made significant clinical observations between the 7C and 14C.

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In the west major advances took place in the 16th century with the development of proper dissection of the body and accurate descriptions of anatomy in the medical school of Padua by Versallius, where Harvey also discovered the circulation of the blood. Eustachius used the term ishmus for the part connecting the two lobes of the thyroid. Paracelsus attributed goitre to impurities in the drinking water and also realised the connection between cretinism, the term used for severe mental retardation, endemic goitre and congenital idiocy. Paracelsus also thought that a diseased organ could be cured by administration of its healthy equivalent organ. In the 16th century the Swiss also described cretins in the mountainous cantons but the cause of endemic goitre was thought to be in the air. It was not however until 1811 that iodine was discovered by a French pharmacist, Bernard Courtois, recognised as an element, isolated and its structure determined by Humphrey Davy (he of miner’s lamp fame). Lugol in 1829 had developed an iodine solution which was sufficiently dilute as to require only one or two drops a day which was useful for short term benefit in reducing the size of goitre and reducing its vascularity, particularly prior to surgery. The relevance of iodine to endemic goitre was recognised in Austria where in 1835 it was recommended by Koestl that iodised salt should be used to reduce the size and frequency of endemic goitre. In 1859 Lombosa advised that iodine be given to all goitrous persons of marriagable age and also to farm animals. In the 1850s Chatin in France found iodine in minute amounts in plants and showed that iodine levels in water, soil and foodstuffs were much lower in regions with goitre and cretinism than in unaffected areas. Iodine was given to school children in a valley in the Pyrenees but in such large doses that it produced toxic symptoms so it was abandoned. At least the toxicity of excess iodine had been recognised as well as its benefits in small quantities but these observations were largely forgotten and iodine prophylaxis for the prevention of goitre and cretinism not reconsidered until the 20C.

In the early 19C Caleb Parry described exophthalmus and goitre but his correct observations were only published posthumously in 1825 so he did not get the recognition that he deserved. However in Wales especially his name is given to the condition more commonly named after Robert Graves of Dublin, who published his accurate observations of four patients in 1833. Von Basedow also described three patients with exophthalmos and goitre and other features of thyroid overactivity, published in 1840, so the condition commonly now known as hyperthyroidism or thyrotoxicosis is largely named after Graves in the English speaking world and after Basedow in the German speaking world. Plummer also described thyrotoxicosis due to an isolated toxic nodule in the early 20C. The term hyperthyroidism was first used by Charles Mayo in the USA in 1907.

In the mid 19C Claude Bernard in Paris and Brown-Sequard founded the concept of internal secretions into the blood in contrast to external secretions, for example from the liver via the bile duct into the gut. This led much later to the recognition that inter-relations between various cells of the body could be influenced by means other than the nervous system and that chemical messengers could have a selective affinity for certain parts of the body and not others. It had been recognised for some time that surgical removal of the thyroid, as well as being hazardous, led to the development of a sluggish and ‘cretinoid’ state and that such states sometimes developed spontaneously particularly in adult women (Gull 1872). Ord in 1877 coined the term myxoedema for the thickened skin to be found in severe thyroid failure or sporadic cretinism. In 1891 George Murray in Newcastle upon Tyne...
announced that he would give a sheep’s thyroid, strained through a handkerchief, to a woman suffering from severe thyroid failure and goitre. He was much mocked by his peers but proven right as the woman recovered over the next six months with repeated treatments every few days and lived to a ripe old age (at the cost of many sheep). Thus began the era of thyroid hormone replacement for hypothyroidism although it was not until 1914 that thyroxine was isolated in crystalline form. In the 1920s Harington described its chemical structure and it was synthesized as levo-thyroxine but not commercially until the mid 20C. Also in Newcastle in 1896 Vaughan Pendred, a local GP, described deaf mutism and goitre in a family, which could be said to be an early recognition of an hereditary feature of certain thyroid disorders. In 1896 Riedel described a form of goitre in which the gland fails due to replacement with hard woody fibrotic material. In the early 20th century Hashimoto, a pathologist in Japan, described multinodular goitre in which a lot of the gland had been replaced by lymphatic cells resulting in thyroid failure and this was the beginning of the recognition that the gland could self destruct, now called autoimmunity.

20th century developments

The 20th century saw significant developments in understanding how the thyroid works and the pathology of thyroid diseases. Iodine was recognised as a constituent of the thyroid and the amount of iodine stored in the gland correlated with the amount of gel known as colloid present in the thyroid. In the early 20th century Iodine was isolated by Hanson and Collip in the 1920s. The risk of damage to the parathyroids as well as the recurrent laryngeal nerve (which controls the vocal cords) during thyroid surgery still remains today but is small in skilled hands. Use of iodine pre-operatively reduced the size and vascularity of the gland. In the 1940s radioactive iodine was introduced by Hetz and Roberts and independently by Leblond for the assessment of Graves’ disease and later for its treatment. In 1943 Astwood used thiouracil and thiouracil in the medical treatment of Graves’ disease and methimazole, the active principle of carbimazole, was synthesised around 1950. Earlier in the 20th century orbital decompression was introduced for severe exophthalmos and in the 1970s steroids were injected behind the eye to reduce the swollen eye muscles in this condition.

Developments in other endocrine glands, particularly the pituitary, had relevance to understanding the way that the thyroid is regulated. In 1963 the technique of radioimmunoassay was developed by Berson and Yallow (who got a Nobel Prize, after Berson died) allowing the measurement of tiny quantities of hormones (10x minus 9 = one thousand millionth of the molecular weight per litre) in the blood. This enabled the measurement of Thyroid Stimulating Hormone (TSH) from the pituitary and confirmed that it rises when the thyroid fails and is suppressed when the thyroid is overactive. It also allowed the recognition of thyroid failure secondary to failure of the pituitary gland due to lack of TSH or of the hypothalamus higher in the brain which secretes Thyrotrophin (TSH)-Releasing-Hormone (TRH). TSH measurement in the cord blood of newborn infants or obtained five days after birth in a spot of blood from a heel prick, was developed as a mass neonatal screening programme in the 1970s in the USA, UK and other developed countries for the detection of congenital hypothyroidism enabling early treatment and the prevention of mental impairment. It was also recognised that the fetus needs iodine from the mother in the first three months of gestation until its own thyroid is formed. Giving iodised oil in appropriate quantities to women of reproductive years in iodine-deficient communities dramatically reduced both the incidence of goitre and of congenital cretinism in their children. It is beginning to be recognised that even in Great Britain in the 21st century many schoolgirls aged 15 or 16 are showing biochemical evidence of mild iodine deficiency and there is a strong case for introducing an increased iodine intake via iodised bread or salt to prevent their subsequent children from suffering mental impairment. Other developments in the late 20th century included the accurate measurement of both total and free levels of T4 and T3 in the blood, both usually raised in thyrotoxicosis, and T4, but seldom T3, reduced in hypothyroidism. It was learnt that thyroid function and thyroid tests can be disturbed in non-thyroid illness and therefore these tests can sometimes be misleading. The tests may also rarely be disturbed if there is resistance to thyroid hormones due to alterations in the receptors on various cells.

What of the late 20th and 21st Century?

The last two decades have seen rapid advances in understanding how the inside of individual cells function and how they work together; how failure of a single enzyme can lead to failure of development at each of the several stages of the development of the thyroid in the fetus, and the genes which regulate these enzymes have been identified. The full genetic processes which lead to Graves’ disease affecting some, but not other, members of families in which thyroid diseases are common, or even isolated sporadic goitre and thyroid cancers, remain to be elucidated. These and other such developments will in due course lead to new and more focused treatments for thyroid disorders. Progress may seem slow but it takes time to translate the accumulated wisdom of generations into effective clinical practice as can be seen from the long history and still incomplete knowledge of the way the thyroid works. There are many scientists and clinicians across the world working in the thyroid field and one should remain optimistic that these will lead in due course to further advances in even better diagnosis, treatment and management of thyroid diseases.

I am pleased to acknowledge the late Dr VC Medvei for his excellent book entitled A History of Endocrinology, published in 1982 by MTP Press Ltd from which I obtained most of the dates and much of the material summarised in this article and to Professor Graham Williams of Imperial College London for his account of the more recent developments in the field of thyroid cell biology. I have tried to give credit to the original observers and investigators of key developments in the history of the thyroid but errors and omissions are entirely my own responsibility.

Dr Tunbridge has had a long and distinguished career in medicine, with a particular interest in thyroid disease. He retired in 2003 but continues to retain an interest in the thyroid and is a patron of the BTF.

All images courtesy of The Wellcome Library, London.
Why do some people with an over-active thyroid have problems with their eyes?

By Marian Ludgate. Professor of Molecular Endocrinology, School of Medicine, Cardiff University.

Readers of this newsletter will be very familiar with a thyroid described using the terms hyperthyroid (over-active) and hypothyroid (under-active). You will probably also be aware that in most people with hyperthyroidism the cause is Graves’ disease (GD). Graves’ is an autoimmune condition, which means that the immune system designed to protect us from infections starts to attack components of our own organs and cells. In GD, the immune system makes antibodies (the part of the immune system circulating in our blood) to the thyroid ‘on/off’ switch. The switch is usually regulated by TSH, the hormone produced by the pituitary, and which is measured in thyroid function tests. Antibodies to the switch are able to activate the thyroid leading to increased growth and production of thyroid hormones (thyroxine, T4 and tri-iodothyronine, T3). They are called thyroid stimulating antibodies (TSAB) and are even able to cross the placenta – the reason it is important to have them under control when pregnant.

Some people with GD also experience a distressing eye disease which has several names; I’ll call it thyroid eye disease (TED). In TED the tissues behind the eye, which usually provide protection within the orbit, are greatly enlarged by two main processes. The first is the over-production of a glue-like substance, which acts just like wallpaper paste and has the ability to absorb 1000 times its own weight in water. The second is expansion of the fat tissue within the orbit. This is unusual in itself since fat in other parts of the body reduce in those with hyperthyroidism; weight-loss is a classic sign of GD.

Fat in the orbit is different from the fat around our middles or under the skin since it develops in the foetus from the same type of tissue as the brain. All fat is ‘terminally differentiated’ which means that it is unable to expand by cell division. Individual cells can get bigger by taking up fat but to generate more fat cells, precursor or ‘stem cells’ have to differentiate into fat, a process called adipogenesis. In the lab we are able to induce adipogenesis using a cocktail of hormones, including insulin. Other factors also promote differentiation, especially one of the drugs used to treat type 2 diabetes and which is best avoided by people with this condition and GD. The ‘stem cells’ from people with TED always differentiate better than those from people who do not have GD or TED. It is thought that in our bodies, mature fat cells produce a factor, similar to the diabetes drug, to induce adipogenesis in ‘stem cells’. I’ve included a figure to summarise fat cell differentiation and also to illustrate that during adipogenesis the newly forming fat cells also express the thyroid switch.

So can the TSAB that cause hyperthyroidism also stimulate adipogenesis? Our studies suggest that they are able to start the process off – but are not able to carry it through to a fully mature fat cell. Results from other scientists, using a highly purified and concentrated form of TSAB, showed some evidence of more mature fat cells being generated.

So how come not all people with GD get TED? Our current experiments are trying to unravel differences in the control mechanisms operating in orbital ‘stem cells’ to discover whether these may be less effective in those with TED and hence explain this.
My Story

Phil Thomas was diagnosed with an overactive thyroid (hyperthyroidism) in 2006, when he was 47.

He recounts his sometimes difficult struggle to ‘normal’ health:

‘What a journey I’ve had. At first I didn’t realise there was anything wrong or that I even had a problem. I started to lose weight around about 2004 although it could be longer; it’s difficult to pinpoint when it actually really started, however, ‘nothing wrong there,’ I thought - I needed to lose a few pounds. The good thing was, I could eat anything and as much as I wanted - cooked breakfasts, doughnuts and chocolate, great. Not that I actually ate mounds, but I was still losing weight. I know it seems crazy to think that now, but I was rushing around like a teenager and I put it down to being busy and on the go all the time. I had bags of energy and never really felt tired, not even my young boys could keep up with me.

‘I had a very hectic and stressful job, but I also had loads of pastimes. I volunteered, did amateur dramatics and I could stay awake all night and not feel tired. People always asked me where I got my energy from. My family and friends, however started to get concerned and notice symptoms, which included shaky hands, weight loss, bulging eyes and sweating more. I then started to notice my heart was racing most of the time. I could actually feel the heart palpitations, however, it was only when I saw some photos of myself, that I realised how gaunt my face looked and how my clothes were literally hanging off me. That’s when I started feeling anxious about things.

‘But even then, it was only after constant nagging from my wife and family that I decided to go to my doctor. As I was describing the above symptoms he started to write a prescription for Carbimazole and a beta blocker (my heart was well over 150 beats per minute just sitting in his office) and he said that he thought I had an overactive thyroid, which proved correct. That in itself was quite a shock.

‘I started going for a blood test every three months and came under a consultant at my local hospital. After going through three years of changing my drug (Carbimazole) dose up and down every three months, my consultant said that it would be a good idea if I went for radioactive iodine as this might help in the long term to stabilise me. So taking advice from my consultant that’s exactly what happened, I went to hospital and had the iodine treatment.

‘Unfortunately they gave me too much iodine, and I then went the other way; and became very underactive, just my luck!

‘Here now starts a whole new chapter… I started putting on weight, however, the first few months after the iodine my moods become very low and I became extremely tired, in fact there were times when I just didn’t want to get up and go to work. I actually had five weeks off work with stress and depression; they didn’t tell me about this, which hit me quite hard. This was a very tough period for me and it is only in the last 18 months I’ve started to stabilise. I certainly did not think it would take eight years to get this far.

‘The past few years have been quite a roller coaster ride of emotions - up and down on Carbimazole and levothyroxine; and one thing that still irks me is when the doctor asks me if I’m feeling normal today. I’d like to know what normal is, having not felt normal for the last eight years, I’m not sure I know what normal is these days.

‘I still battle with my weight and I get nervous every time I go for a blood test but there is light at the end of the tunnel - I only have a check once a year now, and at the moment I seem to be reasonably stable.’

Comment by BTF medical advisor:
Phil’s story illustrates several important points. He had Graves’ disease and by the sounds of it, it was quite severe and went on for a long time. Some people, like Phil, feel great when they are hyperthyroid. They have a lot of energy and can eat anything and not gain weight. However, the thyroid over-activity eventually takes its toll and wears the body out as Phil found out. In about 20-40% of people treated with Carbimazole for Graves’ disease, the over-activity is cured after a course of treatment. If there is still a need for Carbimazole after one to two years, the message is clear that some other form of treatment is required, such as radioactive iodine. Some years ago, there was a widespread trend among endocrinologists to give small amounts of radioactive iodine, aiming for a cure, without making the patient hypothyroid. The overall experience, however, was that the majority of patients ended up having multiple treatments and in the end they became hypothyroid anyway. This has led to the usual current practice of giving one single larger dose of radioiodine. Ideally patients should not have to go through an underactive phase after radioiodine. Liothyronine can be started as soon as the thyroid hormone levels have dropped to just below normal, or even before if there is an obvious trend in the thyroid hormone levels. Liothyronine tablets then take over and keep the thyroid hormone levels normal. In practice transient hypothyroidism unfortunately is common, for a variety of complex reasons.

I think the reasons why Phil may still not be feeling right are complex and his question ‘what is normal?’ is poignant. The prolonged phase of hyperthyroidism and the hypothyroidism that sometimes follows radioiodine no doubt will have their contribution. Having gone through a period of ill health, whatever the condition, often leaves people physically and emotionally exhausted. What does not help is uncertainty and one thing that doctors can do is provide people like Phil good quality information at every stage of their journey so that they are informed about what to expect, and make shared decisions about their treatment.
Research

Research update

The BTF has been involved in two studies recently carried out by research teams at Newcastle University.

The BTF provided feedback on the patient surveys used in the following study via the BTF members panel:

1. Study of Optimal Replacement of Thyroxine in the Elderly (SORTED) results

Research has shown that thyroid function decreases with age especially in people over 80. Older people with an under-active thyroid may need lower thyroid hormone doses.

The BTF has been involved in two studies.

The purpose of the SORTED 2 study was to explore patients' perceptions of the design of SORTED 1. People who took part in the trial and those who did not want to take part were interviewed. There was a lack of concern about having an under-active thyroid and a strong belief that its control was based on blood tests. In addition, easing the burden of travel requirements, flexible appointments, reducing anxiety associated with additional visits and minimising the impact of the intervention could increase participation in the main trial. Those who withdrew from the study cited symptoms which had worsened above a tolerable level. The participants who completed the study were generally satisfied with the study design.

SORTED 3 was a database search of 2688 patients aged over 80 at four GP practices. A high proportion of people in this age group (15.3%) were treated with levothyroxine. Approximately three-quarters of people started levothyroxine when they were aged over 70 with three-quarters of those having thyroid function levels below the recommended level for starting levothyroxine (their TSH was <10 mU/L). Elderly patients who were being treated with levothyroxine had a higher risk of death, independent of other relevant factors, than those not taking levothyroxine; this effect was confined to non-smokers.

It was concluded that a research study of a larger group is needed to find out whether treating older people with lower doses of levothyroxine will improve health. To enable elderly people to take part in studies researchers need to actively seek to reduce the burden of participation.

2. Patient Knowledge of Anti-thyroid Drug-Induced Agranulocytosis

With input from patients through a BTF survey, a paper has recently been published in the European Thyroid Journal on Patient Knowledge of Antithyroid Drug-Induced Agranulocytosis. (Eur Thyroid J, 2014 (DOI:10.1159/000367990).

Agranulocytosis is a rare but serious side effect of antithyroid drugs and the objective of the survey was to ascertain the knowledge of patients and review the quality of information available on the internet. A questionnaire was completed by patients receiving antithyroid drugs. Patients attending endocrine clinics who were receiving antithyroid drug treatment (group A, n = 33) were interviewed. A further national cohort of patients (group B, n = 100) treated with antithyroid drugs, participated in an online survey. Results: 60.9% of responders were not aware of the common symptoms of agranulocytosis; 18.6% had never received any information about side effects. Of the 108 patients who recalled receiving information, 30% rated the quality as ‘poor’ or ‘not good at all’. Structured interviews of group A patients revealed that almost half (45.5%, 15/33) had experienced symptoms that could be indicative of agranulocytosis, but only 53.3% (8/15) had a blood count checked. A review of 20 selected patient information internet sites revealed a significant variation in advice given to patients. The study concluded that inadequate knowledge about agranulocytosis among patients receiving antithyroid drug treatment is common. The available information on the internet is variable and inconsistent.

The findings from this study lead to the conclusion that there is a need for a robust strategy in order for anti-thyroid drug-induced agranulocytosis to be recognised early by patients and appropriate action to be taken. This has to be based on uniform, authoritative, high-quality patient information about side effects.

New UK trial on thyroid eye disease

Recent laboratory studies across different international centres have identified a role for a molecule called IGF-1 as playing a central role in the development of thyroid eye disease (TED). A new antibody which blocks the binding of this molecule to cells has been developed in recent years. Last year, a large international multi-centre trial commenced to recruit patients in order to determine whether this treatment would be clinically effective for patients with active TED. The NIHR Biomedical Research Centre at Moorfields Eye Hospital is the only UK Centre offering patients recruitment to this trial. We are delighted to have brought this trial to the UK and to be able to offer our patients the choice of either standard treatment with steroids, or to be recruited into this exciting new study," said Mr Daniel Ezra, Research Lead for the Oculoplastics department at Moorfields. It is anticipated that recruitment will continue for the next 12 months.
BTF Research Award update

BTF Research Award 2013 winner final report: An Exploratory Pilot Study of Peripheral Blood MicroRNA Markers in Patients with Papillary Thyroid Cancer

Dr Petros Perros and Professor Simon Pearce, Institute of Genetic Medicine, and Northern Centre for Cancer Care, Newcastle upon Tyne have sent a final report on their research.

About 2500 people are diagnosed with thyroid cancer in the UK every year. It is one of the fastest rising cancers among women. The majority of people who are diagnosed with thyroid cancer survive for many years, but have to have checks regularly as the cancer can return even 30 years after the original diagnosis. In about one third of people who have been treated for thyroid cancer, the conventional tests to check if the cancer has come back are difficult or impossible to interpret. The burden on the lives of these patients imposed by the uncertainty about their cancer is significant. New technologies and tests have been emerging for the diagnosis of cancers. One of these is detecting ‘microRNAs’. These small chemicals are thought to be released by cancer cells and may be used as markers of cancer. A number of studies have already shown promising results in thyroid cancer, but have concentrated on detecting microRNAs in tissue samples. We wanted to explore whether such markers could be found in blood samples of patients with thyroid cancer, as blood is much more accessible and convenient than biopsies or other complicated investigations. With generous support from the British Thyroid Foundation we were able to undertake this project. Blood samples from ninety patients with a history of papillary thyroid cancer were studied. We used state of the art technology and probed for all microRNAs that could be identified in the blood samples. We were able to identify up to 178 microRNAs in blood samples. Of these, 18 microRNAs showed an association with metastatic thyroid cancer. One microRNA was particularly promising, which has not been reported to be associated with thyroid cancer, though it has been implicated in breast, ovarian, pancreatic cancer and malignant melanoma. Three other microRNAs previously reported to be differentially expressed in thyroid cancer tissue were also found to be associated with metastatic thyroid cancer in our study.

Our findings suggest that it may be possible to use microRNAs as markers of thyroid cancer in a blood sample. Our study has also identified a potential new microRNA marker of thyroid cancer, not previously described. These data are promising but must still be interpreted with care and must be regarded as preliminary. Additional work is required to confirm and explore the potential role of such tests in clinical practice.

Our team wish to thank the BTF for financial support and our patients from the Thyroid Cancer Clinic at the Northern Centre for Cancer Care, Newcastle upon Tyne for donating blood samples.

Research news

3d bioprinted thyroid gland in 2015

Researchers and scientists working with a company called 3D Bioprinting Solutions, located in the Skolkovo innovation center, near Moscow, are reported to be making tremendous progress in the field of bioprinting functioning organs and have chosen to start with the development of a bioprinted thyroid gland, hoping to create the world’s first 3D printed organ in 2015, using stem cells as the ‘ink’ for the printer. They have chosen the thyroid because of its simplistic structure.

Headed up by Vladimir Mironov, the researchers at 3D Bioprinting Solutions intend to begin their initial experimentation with mice. The printer works by using stem cells which are created by utilising fat cells within a patient. These cells are placed down layer by layer, and then they are transformed into an aggregation of cells that are known as spheroids. The hydrogel that is used in order for the cells to take shape then dissolves, leaving the printed organ. According to Mironov the rejection of such organs should be minimal, since they are made out of the patient’s own stem cells.

Source: http://3dprint.com/23805/bioprinted-thyroid-kidney/
work to validate a new test and so even if it does turn out to be useful it will not become available for a while yet. This does not mean that conventional ways of assessing people for recurrence are useless. The fact that your specialist feels annual assessments are adequate implies that he is not overly worried. When the thyroglobulin test is unhelpful, ultrasound of the neck can be a very reliable way of ensuring there is no recurrence and perhaps that is worth discussing with your doctor. I sense that your concerns about recurrence are not shared by your specialist and it would be worth asking the question of how high does he think is the probability of recurrence in your case. You may find it is less than you think.

Vitiligo and thyroid

JH asks: Do you have or know where I can get any information regarding a link between vitiligo and thyroid? I was diagnosed with an under-active thyroid several years ago and recently I have developed vitiligo. I have only found one doctor who thinks that there is a link between the two as they are both autoimmune diseases. I would like to have more information, so any help would be appreciated.

Our medical advisor replies: There is an indirect connection between thyroid disease and vitiligo. Both are autoimmune conditions. Having one autoimmune condition makes others more likely. However they do not have a direct impact on each other, ie if one improves it does not necessarily mean the other one will. If two do co-exist, then that means there is an increased chance of further autoimmune conditions. Thyroid disease and vitiligo can be part of a cluster of conditions called Autoimmune Polyglandular Syndrome type-2 (APS2). In this condition, other autoimmune conditions are more likely to occur, but in many will not. This includes conditions such as Addison’s disease, diabetes, hypogonadism, coeliac disease and pernicious anaemia. Patients with APS-2 should be screened for these conditions every 12-18 months, or if they develop relevant symptoms.

Swallowing issues and hypothyroidism

JA asks: I am a speech and language therapist working with people with learning disabilities. I have noticed that a significant number of people with Down’s Syndrome who have hypothyroidism complain of difficulty swallowing; they sometimes have a hoarse voice also, though I have not looked at this in detail as my assessments have been focused on the swallowing problems. I wondered if you or anyone in your association is aware of the incidence of swallowing problems for people with under-active thyroid, the causes and any related research, as well as treatment options.

Our medical advisor replies: People with Down’s syndrome are at a significantly increased risk of autoimmune hypothyroidism. In some people this can be associated with a goitre, but only in exceptional circumstances would it be large enough to cause voice or swallowing problems. It is possible that it is more related to the neuromuscular problems that can occur in Down’s syndrome.

Recovery time after an operation

EC asks: In June this year I was taken ill on holiday. I was taking Carbimazole for an over-active thyroid and the tablets caused my white blood cells to drop to 1. I had to return home and in September this year I had my thyroid removed. I had the operation done privately so I’m now under my GP. I had a blood test recently and my thyroid and calcium levels were fine, but what is worrying me is this whoosey feeling I have inside, it’s like a wave that goes through my body almost like I’ve had too much to drink. My doctor is dismissive and says I’m too impatient and it could take six months before I’m back to normal. I would like your advice please. I am just desperate to be normal again and be able to swim twice a week and take long walks.

Our medical advisor replies: It is not unusual for people not to feel right for several weeks after an operation. This seems to be related to the anaesthetic in most cases, and the time course depends very much on the individual patient. Some recover quickly, others take longer. It is reassuring that your thyroid levels and calcium are normal. It is very likely that you will start to feel better soon. It is exceptional in my experience for it to take as long as six months. My suggestion would be to try and get into your previous daily routine. Increase your activity gradually and steadily, avoid excesses (eg alcohol, caffeine) and eat healthily.

Recurrent infections following a thyroidectomy

AD asks: I had thyroid cancer two and a half years ago at the age of 24. I have had my thyroid removed and had successful radiotherapy. I am now on 175mcg levothyroxine a day and all is going well. However, I keep getting infections, and I am
being told it is because I am ‘run down’. Does the thyroid suppress your immune system? I know that if it is too low it does, however I know my levels are higher than normal so I was just wondering if it is to do with a bad immune system, or just bad luck!

Our medical advisor replies: It is bad luck rather than the thyroxine replacement I’m afraid. There is no reason why you should be more prone to recurrent infections following a thyroidecmy with adequate thyroxine replacement.

Thyroid cancer and eye disease

DT asks: Our son is experiencing problems with his eyes prior to and after the complete removal of his thyroid gland a few months ago, due to papilliary thyroid cancer.

He started having problems with his eyes about a year and a half ago and was told he had a scratch on his left eye and ‘dry eye’. He had bouts of this for a few months and said his vision was wavy, as if he was looking through water. He became worried and went to A & E this summer and was referred to the ophthalmology department.

Around this time, also, he was diagnosed with cancer of the thyroid. He still kept his appointment at the eye hospital but they could find nothing wrong.

Since his surgery, he says the wavy lines are not so frequent and only happen on occasion. He often experiences double vision in his right eye but says if he covers his left eye with his hand, his vision becomes more focused. He has been suffering from headaches which he sometimes describes his left eye with his hand, his vision becomes normal so I was just wondering if it is to do with a bad immune system, or just bad luck!

Our medical advisor replies: There is no link between thyroid cancer and eye disease as far as I am aware and it does not cause thyroid eye disease. My guess is that these are two separate problems.

If your eye hospital is not easily accessible another option would be to visit a really good optometrist. Some of them are trained to look for eye abnormalities and can refer direct to eye specialists rather than you having to go through your GP again. It may be useful to have him looked at by someone new.

Local Groups

Please check the BTF website (www.btf-thyroid.org) for the latest details. Please also check before you attend a meeting that it has not had to be cancelled due to poor weather conditions.

Birmingham

Next meeting: Check the BTF website for details.
Location: Check the BTF website for details.
Donation: £2 voluntary donation for venue costs and refreshments.
Contact: Janet Tel: 0121 628 7435 or email: janetdmp@googlemail.com

Cambridge

Next meeting: Saturday 21 March at 10am.
Location: Friends’ Meeting House, Jesus Lane, Cambridge CB5 8BA.
Donation: Suggested minimum donation: £3.
Contact: Mary on 01223 290263 or email her on butterflyecho@hotmail.com

Edinburgh

Next meeting: Tuesday 28 April at 7.15pm. There will be a talk by Professor Mark Strachan, topic to be decided. Check the BTF website for further details.

The Edinburgh BTF Support Group meets on the last Tuesday of the month except for school holidays.

Location: Liberton High School, Gilmerton Road, Edinburgh, EH17 7PT.
Contact: Margaret Tel: 0131 664 7223 or email: M2mcgregor@aol.com

Leeds (Wharfedale)

Next meeting: Wednesday 25 March at 7pm.
Location: Caroline’s house in Leeds 21 (five minutes from Harewood House).
Donation: No charge but a small donation to the BTF would be appreciated.
Contact: Caroline on 0113 288 6393 or email cfields237@btinternet.com for more information.

London

Next meeting: Saturday March 28 from 10am to 1pm.
BTF LOCAL COORDINATORS

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

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<th>Contact Information</th>
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<tr>
<td>Birmingham</td>
<td>Janet (PC,CS,RAI,PH)</td>
<td><a href="mailto:janetdmp@googlemail.com">janetdmp@googlemail.com</a></td>
<td>0121 6287435</td>
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<tr>
<td>Cambridge</td>
<td>Mary (O,Rl,U)</td>
<td><a href="mailto:butterflyecho@hotmail.com">butterflyecho@hotmail.com</a></td>
<td>01223 290263</td>
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<td>Edinburgh</td>
<td>Margaret (PC)</td>
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<td>Caroline (O,U)</td>
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<td>London</td>
<td>Denise (U)</td>
<td><a href="mailto:denisesims@btf-thyroid.org">denisesims@btf-thyroid.org</a></td>
<td>07984 145343</td>
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<td>Notts/Derby</td>
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BTF TELEPHONE SUPPORT CONTACTS

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

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<td>Dave</td>
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<td>Jackie</td>
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<td>Ursula</td>
<td>(U)</td>
<td></td>
<td>07720 659849</td>
<td></td>
</tr>
<tr>
<td>Colin</td>
<td>(O,Rl,U)</td>
<td></td>
<td>07973 861225</td>
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<tr>
<td>Olwen</td>
<td>(O,Rl,U)</td>
<td></td>
<td>01536 513748</td>
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<tr>
<td>Jane</td>
<td>(GR,RI,TED,G,U)</td>
<td></td>
<td>01737 352536</td>
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<tr>
<td>Peter</td>
<td>(TED,GR)</td>
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<td>01200 429145</td>
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<tr>
<td>Helen</td>
<td>(O,TS,TED)</td>
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<td>01858 525770</td>
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<tr>
<td>Penny</td>
<td>(Ch)</td>
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<td>01225 421348</td>
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KEY

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

OUR PARTNER ORGANISATIONS

AMEND Tel: 01892 516076 www.amend.org.uk
Hypopara UK Helplines: 01342 316315 and 01623 750330 www.hypopara.org.uk
Thyroid Cancer Support Group Wales Tel: 08450 092737 www.thyroidsupportwales.co.uk
Butterfly Thyroid Cancer Trust Tel: 01207 545469 www.butterfly.org.uk

Cancer52 www.cancer52.org.uk
Thyroid Eye Disease Charitable Trust Tel: 0844 8008133 www.tedct.org.uk
British Thyroid Association www.british-thyroid-association.org
British Association of Endocrine and Thyroid Surgeons 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</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Full: £20 per year</td>
<td>Full: £17 per year</td>
<td>£200 by cheque</td>
</tr>
<tr>
<td></td>
<td>Concession: £10 per year</td>
<td>Concession: £8.50 per year</td>
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</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>
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</thead>
<tbody>
<tr>
<td>£25 Europe</td>
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<td></td>
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<tr>
<td>£35 Outside Europe</td>
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Concession: unwaged and children under 18. Please help us by ensuring that you pay the correct subscription.

The topic of the Seventh International Thyroid Awareness Week (25-31 May 2015) will be on the causes and treatment of hypothyroidism. Go to: www.btf-thyroid.org/index.php/campaigns/hypothyroidism-care-strategy for more information.

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. facebook: BritishThyroidFoundation twitter: @britishthyroid