Thank you for your support - we’re celebrating 25 years!

A word from BTF Director and Founder, Janis Hickey:

Twenty five years ago, after experiencing the loneliness of being diagnosed with a thyroid disorder and given very little understandable information I set up the BTF from my box room. Today, four office moves and a quarter of a century later, we are a national charity with 4000 members, six members of staff at HQ and many more volunteers.

Successes

BTF’s focus has always been to provide clear, concise and trusted information for patients and their families. Our information leaflets, first printed in 1992 and regularly updated are still proving as popular as ever and our thyroid cancer booklet is now in its third edition. We are also planning our second children’s conference in May 2017. The BTF Research Award, introduced in 1997, has enabled researchers to ‘kick start’ their research into thyroid disorders and possible new treatments. Several studies supported have led on to much bigger research projects. The Award, originally for £5000 per year is now £20,000 and in the past three years two awards will have been designated specifically for research into hypothyroidism, the most common thyroid disorder. Since 2009 the BTF has been a National Institute for Health Research partner, meaning that studies we fund are automatically eligible for consideration for Clinical Research Network support.

Recognition and acceptance of the need to support people with thyroid disorders and for the patient to be listened to is so important and by building relationships with medical and health professionals and organisations such as the Society for Endocrinology, the British Thyroid Association, and the British Association of Endocrine and Thyroid Surgeons we have been able to put the patient’s perspective across. We are now regularly invited to present patient concerns at conferences, to take part in steering committees for new projects and to collaborate on research studies.

The number of fantastic fundraisers who raise sometimes staggering amounts for us has continued to increase and we are amazed at the incredible challenges some of them take on (sixty hour non-stop endurance race on the Great Wall of China - any more takers?! See page 5). The number of hits on the BTF website has increased threefold in the last year and the BTF Facebook groups are an ever more popular way for people to support each other.

From day one we have also had local support groups around the country who successfully provide invaluable support and information and we have many other volunteers providing administrative and IT support, a helping hand at events and with selling Christmas cards – all the things that are so important to keep us ticking over.

Challenges

We are proud of what we have achieved but have some challenges ahead: Our membership numbers are lower largely due to the comprehensive BTF website and the effectiveness of the information we provide, and we need to look ahead to new ways to fund our work to help thyroid patients now and in the future.

We want to make sure we are still a relevant organisation in another 25 years and support all our members now and in generations to come. We have a lot of work still to do and your support as members is vital for us to continue funding research into new treatments for all types of thyroid disorders and for us to continue providing reliable information for all.

Thank you for your continued support.

Best wishes
Janis Hickey
Welcome to....

Bethany Frost who has joined us as an apprentice for 12 months. Bethany is studying Business Studies at Harrogate College and spends three days a week with us helping out with administration as part of her course.

Patron Josef Craig wins bronze!

BTF Patron Josef Craig MBE won a bronze medal in the S8 100m freestyle swimming with a personal best at the Rio Paralympics. Josef, who has mild cerebral palsy, was reclassified into a harder group at Rio and is the first person to win successive medals after moving up a category (he won gold at London 2012 not long after being diagnosed with Graves’ disease). His biggest supporter, his mum Kim said: ‘Josef is very happy with his performance. Coming home with a bronze medal and a huge personal best after his reclassification is outstanding. As usual Josef is always striving for more so has bigger aspirations for Tokyo. He is proud to be a BTF Patron and sends his best wishes to everyone’.

News from BTF

BTF Patron Michael Tunbridge, retired Consultant Physician and former Postgraduate Dean of Medicine, Oxford, has been a staunch supporter of the BTF from the start, being a Trustee on the BTF’s first Board. He has sent the following words of support to us on our anniversary:

‘It has been a pleasure to see the BTF develop for the benefit of patients and, through its links with the British Thyroid Association (BTA), for professionals too, especially in its support for thyroid research. The BTA has helped to write the leaflets and provide professional advice via the BTF for people with a variety of thyroid disorders; the BTF keeps the BTA informed of patients’ concerns.

‘The 125th anniversary of George Murray’s discovery celebrated in Newcastle in June 2016 highlighted the impressive quality of the papers presented about the basic science and genetics underlying thyroid disorders as well as a wide range of other endocrine diseases, which augers well for our future understanding of the mechanisms of disease. Hopefully this will lead to improved diagnoses and treatments.’

‘It is all the more important that the BTF continues to flourish in helping patients and their relatives to keep abreast of these developments and providing support for those in need as well as keeping the feet of professionals on the ground! It has been my privilege and pleasure to have worked with so many distinguished colleagues and friends and also to have been involved with the BTF since its inception, subsequently as a Trustee and now a Patron. Congratulations to Janis Hickey who founded the BTF and to the team on reaching its 25th anniversary. May the BTF long continue to flourish.’

See the full version of this article at www.btf-thyroid.org/about/25years
Farewell to....

Professor Geoff Rose
whose term of office
as a BTF Trustee has
come to an end.
Professor Rose, a
Consultant
Ophthalmic
Surgeon at
Moorfields Eye Hospital
became a Trustee in 2010. We thank
him for all his support over the years.

New membership prices
From October 2016 the cost of membership
will be £25 for full rate, £15 for
concessionary rate and £200 for life
membership. Overseas membership
(electronic newsletter only) will be £25 (in
Sterling). The last increase in membership
was in 2006.

Electronic newsletter
Email join@btf-thyroid.org if you would like to
receive your email electronically. Choosing to
receive BTF News by email will allow your
subscription to be used more effectively for
patient benefit.

Gift Aid reminder
The Gift Aid Scheme at BTF has been in
operation since we started in 1991. Funding
has never been tighter for all charities,
including ours and the money we can collect
from Gift Aid is vital for us to continue to help
fund research and develop our projects. Last
year we received £9000 extra income
through Gift Aid.

If you are a taxpayer, ticking the Gift Aid box
on your renewal form and for any donations
you make means we can claim an extra 25p
for every £1 you give and it won’t cost you
any extra. The tax could have been paid on
income or capital gains.

Some important points:
You must tell any charities you support if you
stop paying enough tax. If you pay less than
the amount of Gift Aid claimed on all your
donations in that tax year it is your
responsibility to pay the difference.

If you have taken out membership on behalf
of a minor, you may sign a Gift Aid
declaration in relation to gifts made prior to
his or her eighteenth birthday.

If you pay tax at the higher or additional rate,
you can claim the difference between the
rate you pay and basic rate on your
donation. Do this either through your Self
Assessment tax return or by asking HM
Revenue and Customs (HMRC) to amend
your tax code.

Please inform us if you change your name or
address.
See www.gov.uk/donating-to-charity/gift-aid

New offices
We have settled in well to our new offices
now. Thank you to Monica Jenkins from
Settle for sending in a fascinating letter of
her childhood experiences visiting her great
grandparents who owned a farm on the site
of our new offices on Hornbeam Business
Park.

Thyroid cancer forum
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 can meet other patients,
listen to leading experts and have the
opportunity to ask questions.
To book your place now email:
enquiries@butterfly.org.uk

Successful grant application
We are grateful to have received a grant of
£500 from the Paristamen CIO charity
(www.paristamen.org.uk). The Yorkshire
based foundation supports small charities
who are able to demonstrate strong
evidence of compliance with charity law and
being well managed.

Take part in a trial on a new
thyroid nodule examination
technique
The ElaTION trial is looking at the potential
benefit of using a technique called Real Time
Elastography (RTE) alongside the standard
ultrasound-guided Fine Needle Aspiration
(FNAC) in the examination of thyroid
nodules. It is believed that RTE can help
improve the accuracy of the diagnosis of
thyroid nodules which could reduce the
number of FNAC required before a diagnosis
is made. It could also decrease the number of
patients undergoing unnecessary surgery.
Recruitment is planned to finish at the end of
September 2017. Follow up will last until
October 2018.

The lead researchers are keen to recruit as
many patients as possible so they can be
sure that numbers are big enough to make
the eventual results reliable.

Who can take part?
If you are: aged 18 or over;
have at least one thyroid nodule; and have
not had a previous FNAC in the last 12
months.
The trial is taking part in hospitals
nationwide. Contact the ElaTION team on
0141 414 9013, or email
elation@trials.bham.ac.uk for a full list of
hospitals.
More information is available at
www.birmingham.ac.uk/ElaTION

Order your BTF Christmas
cards
We have a new collection of traditional and
contemporary Christmas cards for sale,
which will raise valuable funds for the BTF
and let people know about our work.

You can order your cards now by filling in the
flyer enclosed with this newsletter or by
visiting the BTF website. Cheques should be
made payable to the ‘British Thyroid
Foundation’ and sent to the mailing house
address on the order form (not to BTF HQ).
Iodine project

Following on from the Iodine Global Network (IGN) Meeting held in March 2016 that focused on the role of iodine on pregnancy and iodine deficiency in the UK, a 21 page report has been produced to provide an overview of some of the key issues addressed. The report is going to be distributed to specialists, government health departments and the media amongst others. To download a copy of the report go to: www.ign.org/cm_data/IGN_Annual_Report_2015.pdf

One of the key speakers at the symposium, Professor Peter Laurberg a leading international voice in thyroidology, sadly passed away unexpectedly in June. Dr Mark Vanderpump, National Coordinator of the IGN Group said ‘He will be remembered as a giant of European Thyroidology who had time, friendship, and kind encouragement for everyone – a truly great man.’

Thyroid eye disease

Raising awareness of thyroid eye disease (TED) with warning cards

Dr Anna Mitchell, Academic Clinical Lecturer in Endocrinology, Newcastle, on behalf of the TEAMeD group in which the BTF plays a key role, details results from a service improvement project set up to ‘fast track’ patients to an early diagnosis of TED.

Thyroid eye disease (TED) develops in one in five people with Graves’ disease. Most people with Graves’ disease in the UK are looked after in endocrinology clinics by hospital specialists. However, despite this, some patients still report significant delays before a diagnosis of TED is made. The TEAMeD group was established to try to increase awareness of TED with the hope of improving patient care. We aimed to trial thyroid eye disease ‘early warning cards’ for patients, to see if these could be used to ‘fast-track’ patients to receive an earlier TED assessment.

To do this, we designed credit-card sized TED warning cards, which have a list of the common symptoms of TED and a telephone number for patients to call who develop eye symptoms. We handed out these cards to 171 patients across five hospitals (Newcastle, Exeter, Cardiff, Edinburgh and Leeds) and then waited for three months to see how many telephone calls were received as a result of the cards. After three months, we asked patients for feedback, by email or post, about the scheme.

Over three months, 6% of cards handed out resulted in a telephone contact. One of these calls was managed with telephone advice alone, while the other 10 resulted in an additional clinic review (for nine patients). Of the nine patients who were seen in clinic, five diagnoses of thyroid eye disease were made.

Following the trial, 49 of the 171 patients (29%) gave feedback. Of these 49 people, 45 remembered receiving a card. The number of patients who thought it was helpful to have a card was 40/45 (89%) and 44/45 (98%) had clearly understood what the purpose of the card was. Three responders had called the telephone number on the card because they had developed eye symptoms. Of these, one had found the telephone consultation very helpful, one reported that it was somewhat helpful and one reported that it was not helpful as they had been unable to speak to anyone.

We have found that it is possible to give out TED early warning cards to patients in clinics and that these are generally appreciated by patients and do not result in an excessive number of telephone calls. The scheme enabled an additional five out of 171 patients with Graves’ disease (3%) to receive an earlier diagnosis of TED. It is hoped the scheme will be rolled out more widely in the future.

Children

Following on from the success of the first BTF Children’s Conference in Leeds in 2014 we are delighted to announce we will be holding our next conference in London on Saturday 13 May 2017 at the Abbey Centre in Westminster. If you are interested in coming along and would like to be sent further details please email julia.priestley@btf-thyroid.org

Out and About

International Thyroid Eye Disease Symposium (ITEDs)

Janis Hickey, BTF Founder, spoke about the patient’s perspective of thyroid eye disease (TED) at a symposium in June in London attended by over 300 delegates. Many clinical leaders from all over the world gave insight into the diagnosis, investigation and treatment of TED. The latest research from laboratory-based clinical investigations was presented and discussed.

Thyroid cancer symposium

We were delighted to be invited to have a stand at the Multidisciplinary Thyroid Cancer Symposium hosted by the Royal College of Physicians and Surgeons of Glasgow on 2 September 2016.

Julia Priestley from BTF HQ said: ‘Experts from all fields involved in the treatment of thyroid cancer spoke about the updates and best practice in respect of thyroid ultrasound, pathology, surgery, RAI therapy and the role of the specialist nurse. For BTF the event was an important opportunity to talk to specialists about the work we do and raise the profile of the charity amongst clinicians.’
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

Rachael Harrop and Jo Downes both completed the York 10k in August. Jo raised nearly £800 and said: ‘Our daughter was diagnosed with congenital hypothyroidism through the heel prick test. She was just two weeks old. With the help of the wonderful team at Great Ormond Street and BTF information online, we have over the last four years learnt so much.’

Rachael, who has an underactive thyroid raised nearly £350 and said ‘I pushed myself at the end, thanks to a friend who said he would double his sponsor money if I beat 1 hour 15 minutes so I went for it!’ See Rachael’s ‘My Story’ on page 12.

Sarah Lunt who has recently been diagnosed with an under-active thyroid raised £200 by running the English Half Marathon in September.

Viv Craig raised over £100 from a ‘onesie’ day at work and a cake sale. Her step daughter has congenital hypothyroidism. She said: ‘She is only five but never moans about taking her medication or having to go to the hospital - other than a bit of anxiety in regard to the blood test and is doing really well.’

Natalie Ryan ran her first 10k in September when she took on the Hursley Multi-terrain race in Hampshire. Natalie had a thyroidectomy 15 years ago and has found subsequently having an under-active thyroid challenging. She raised over £200.

Jill Liddington raised £150 by walking the South Downs Way in July. Jill said: ‘I have had hyperthyroidism for five years now and as part of my seventieth birthday celebrations, I walked 80 miles with friends along this beautiful Sussex trail’.

Great North Run

Seven fantastic runners took part in the Great North Run on a hot day in September and raised £2500 for the BTF between them! Adam Perros, Martin Priestley, Mo Bhaskaran, Marika Wiebe-Williams, Liz Killean, Chris Peart and Ian Springthorpe

Many thanks to you all!

Future Fundraisers

Catherine Harper who has an under-active thyroid, is going to zipwire from the Tyne Bridge for us in October to mark her 30th birthday. www.justgiving.com/fundraising/Catherine-Harper

Amanda Hobday, who has had a thyroidectomy is running the Birmingham Half Marathon in October.

Louise Ballantyne, whose mum has an under-active thyroid, is taking on an extreme endurance challenge in China in October. She will be taking part in the Spartan Agoge Great Wall of China challenge which involves running, carrying, crawling, climbing and trekking but with added mental challenges and sleep deprivation for 60 continuous hours! Good luck Louise! www.justgiving.com/fundraising/Louise-Ballantyne

Zoe Haden is running the Cardiff Half Marathon in October. www.justgiving.com/fundraising/ZoeRunsAHalf

Gavin Raby is running the Silverstone Half Marathon next March. His wife has been diagnosed with thyroid eye disease and he is keen to raise awareness. www.justgiving.com/fundraising/Gavin-Raby

Helen Murray is taking part in a 5k run in the Autumn following a recent thyroidectomy and a return to fitness. www.justgiving.com/fundraising/Helen-Murray24

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.

Carole Ingham, long standing BTF local coordinator and BTF trustee who passed away in January has left a legacy to the BTF of £10,000.

Carole was very involved with the annual Bolton Flower Show. Above is a photo of a floral tribute made by her close friends the Berry and Walker families for this year’s flower show.

Anne Yates, who went to Carole’s meetings 12 years ago when she was first diagnosed with a thyroid disorder has donated £1000.

Donations of £155 in memory of Betty Johnson.

Donations of £303 in memory of Ruth Johnson.
Clinical thyroidology – change over 25 years

By John Lazarus, Emeritus Professor of Clinical Endocrinology, Cardiff University and British Thyroid Foundation Patron

The BTF is to be congratulated on achieving 25 years of helping patients and their relatives in relation to all aspects of clinical thyroid disease in the UK. But has anything changed in the management and our understanding of these diseases? I will discuss these changes as seen from a personal perspective.

Hyperthyroidism

For hyperthyroidism, mostly due to Graves’ disease, treatments are the same as 25 years ago. In fact, antithyroid drugs and radioiodine have been used since the end of World War II. Thyroid surgery has been around for much longer but is now much safer. During the last 25 years or so it has been realised that anyone performing thyroid surgery should be doing a minimum number of operations per year and that results should be audited. The British Association of Endocrine and Thyroid Surgeons has taken a lead in this, resulting in many fewer complications of surgery. However, the three treatments currently available for hyperthyroidism are crude, namely blocking with drugs, destroying the gland with radioiodine or cutting the gland out. There is still no consensus as to whether block and replace therapy is superior to antithyroid drug therapy alone. Although we now know much more about the immunological background of Graves’ disease and can measure the thyroid stimulating antibodies (the proximal cause of the thyroid overactivity) more reliably, there are no immune targeted drugs that are available for routine use in therapy. Nevertheless, the discovery of so-called small molecule antagonists to the TSH receptor in The United States holds out hope for a more rational approach to treating hyperthyroidism. Trials are also underway in this country to try and discover the causes of the disease that will hopefully lead to new drug therapies.

Thyroid eye disease

The story is different for the management of thyroid eye disease, Graves’ orbitopathy (GO). We know for example that cigarette smoking is a significant risk factor for this potentially debilitating and sometimes sight-threatening condition. Similarly radiiodine, administration for hyperthyroidism is a well documented risk factor but prevention of GO after radioiodine can be achieved with prophylactic steroid administration. Precise details of this have been developed during the last 25 years. Furthermore, many trials of different immune modulating drugs including steroids and the more specific immune modulating agent Rituximab have been performed. These studies have resulted in much improved management of the moderate to severe forms of GO. Improvement in the signs and symptoms of mild GO has been noted with selenium administration and this drug should be part of the management of mild GO.

While it is acknowledged that low and high maternal thyroid function may cause a reduction in child IQ and have adverse obstetric outcomes the question as to whether to screen all women routinely for thyroid function has not been agreed. China, Spain and India have started or are preparing for universal thyroid screening in pregnancy, but the USA and the UK have not.

Goitre and thyroid cancer

With regard to goitre the use of fine needle aspiration biopsy (FNAB), thyroid ultrasound and other imaging techniques has brought this branch of thyroid disease into the 21st century. Surgery for goitre is now safe with few complications due to the assistance of these techniques as well as surgical skill and training. The question of course is how thyroid cancer is diagnosed from these investigations.
Research is the key
It should be remembered that the advances in clinical management of patients could not happen without appropriate research into all aspects of thyroid disease. The BTF is proud to have played a part in supporting such research. In addition, it must be noted that other disciplines including chemical pathology, nuclear medicine and imaging including ultrasound, computed tomography and magnetic resonance imaging have contributed hugely to biochemical and morphological assessment of the patient with a thyroid problem. Twenty five years ago these techniques were hardly used or not available.

Finally, the development of guidelines for different clinical thyroid disorders, in which the BTF has played a role, has improved the management of patients right across the whole of the UK. Well done BTF! We look forward to the next 25 years.

Long-standing members

We asked some of our members who had been with us from the start why they joined the BTF and how it has helped them.

Ella Atkinson, aged 92, has been a member since 1992.

What thyroid disorder do you have and how old were you when you were diagnosed? I have Graves’ disease and was diagnosed in my mid sixties. I was given Carbimazole daily. The doctor took me off them after five years when I developed a swelling in my neck. At the age of 66 I went downhill and couldn’t eat or walk about at all and went from nine stone to six stone. A consultant from Christie’s hospital came to Barrow hospital and I went there for radioactive iodine treatment. I started to pick up very rapidly. I had no medication for a year and then I have taken 50mcg levothyroxine since.

How has the BTF helped you over the years? I heard about the BTF through the National Osteoporosis Society, which I joined when my mother died aged 93 in 1988. You sent me information when you were starting. Your organisation has been so helpful and informative over the years. I particularly enjoy the letters and up-to-date information in the newsletter.

Mrs Rushton has been a member since 1992.

What thyroid disorder do you have and how old were you when you were diagnosed? I have an underactive thyroid and was diagnosed at 44 years old.

What treatment were you given when you were first diagnosed and how has this changed over the years? I was started on 150mcg of levothyroxine daily, I am now on alternative days of 100mcg and 125mcg.

How has the BTF helped you over the years? In the first years it made me realise I was not alone. I tried to set up a local group but was not successful although people did call me up about my thyroid problems. I like to read the BTF News to see what the local groups are doing now and how the BTF has developed over the years. It has helped so many people realise they can lead a normal life.

Long-standing volunteers

We asked some of our volunteers who have been with us for a long time why they decided to become a volunteer:

Jan Ainscough has been a volunteer at BTF HQ for 15 years.

What is your background? I’m a chartered mechanical engineer, having worked in the automobile industry, the aeroplane industry and the building industry. I joined BTF some 20 years ago when my thyroid was destroyed by radiotherapy after breast cancer surgery.

When and why did you become a BTF volunteer? The first year BTF sold Christmas cards they asked for volunteers for packing and dispatching them and as I lived within walking distance of the office, I volunteered and have been helping in the office ever since. I’m one of the oldest volunteers in both senses!

What do you do at BTF HQ? I enter payments listed on our bank statements on our membership database.

How has the BTF changed since you started? The main change has been the development of the website and different methods of paying the subscriptions. The new office is a joy.

Wilma Beckett has been local coordinator for the BTF Milton Keynes Group for the last 14 years:

Tell us about your background? Before taking early retirement in 2000 I was a senior lecturer in health care at Bedfordshire University.

I have a long history of working in the NHS from starting at age 17 when I commenced my nurse training up until today where I still involve myself in local health care issues.
I have been the BTF local coordinator in Milton Keynes for the last 14 years. I was the first patient to take on the role of Chairman of the BTF trustees.

**Why did you first become involved with the BTF?** In June 2000 I was diagnosed with hypothyroidism. Because of my health background I was aware of thyroid conditions but needed to be more knowledgeable in how I could help myself to get back to feeling normal again. I found a lot of confusing information on the internet and remember how some people were angry and thought that their treatment wasn’t effective. I vowed when and if I got better I would start up a support group in my area. Through my research I found the help and answers that I needed came from BTF. Their affiliation with the British Thyroid Association (BTA) and others provided me with an in-depth view from their research and publications on thyroid conditions.

**What changes have you seen over the years in the type and level of support needed?** I have found that there is still a need for support and personal education. Empowering oneself in getting to know about your thyroid condition should be a priority and would help in working in partnership with GPs/Medics. I refer those first diagnosed to the BTF website for information that one knows is relevant and up-to-date and this is often the first stage that is needed to help them cope with their diagnosis. For those who have a long-term thyroid condition they need to keep abreast of the research that is current and by joining BTF they can obtain this through the newsletter. The level of support is ongoing and can vary from being offered to those first diagnosed to the long-term when a problem occurs.

**Have modern methods of obtaining information (websites etc) affected your group/number of phone calls?** The numbers of people attending the support group and who contact me by telephone fluctuate. The availability of information on the internet means that a lot of, particularly younger, thyroid patients are very knowledgeable about the issues. This means that they sometimes come up with facts or figures that I am not acquainted with and so I have to check for myself, the information they provide. This can sometimes be challenging especially when they quote information from other thyroid patient website, but I can always contact BTF who will pass on queries to their excellent team of medical advisors.

**What do you most enjoy about volunteering for the BTF?** I get the most satisfaction when talking to people and when our OU audience responses on the evaluation forms are complimentary and positive. Newly diagnosed people are often shocked at first and need a lot of reassurance; I welcome those enquiries as I can relate it to my own experience. I started 15 years ago and have met lots of lovely people and their families who have a thyroid condition. Most of our success in Milton Keynes is due to the excellent team of volunteers who are by my side in all weathers spreading the word about BTF.

**What do you most enjoy about volunteering for the BTF Edinburgh Group for the last 13 years:**

Tell us a few lines about your background

I was born, bred and educated in Aberdeen. In the past I have worked as a teacher, youth worker, in local government, as a magistrate and a carer. I have been involved in a number of Scottish charities and I spent 20 years as a Justice on the District Court Bench and 15 years on the Edinburgh Prison Visiting Committee. Currently, in addition to my work with the BTF, I am involved in local community groups as well as doing part-time research in health issues.

**Why did you first become involved with the BTF?** I have had a thyroid disorder (first hyperthyroidism then thyroid cancer) since my early twenties (over 40 years ago) and first became aware of the BTF in 2003. I thought that the experience I had as someone with a thyroid disorder for 30 years, especially with symptoms, diagnosis, medication, treatment and the NHS would enable me to help, support and counsel other thyroid patients.

**What changes have you seen over the years in the type and level of support needed?** The level and type of support remain much the same now as they were 10 years ago. People who attend the Edinburgh support group are generally those who have ongoing problems arising from their thyroid problems. Those who contact me by telephone or email usually have more urgent requests for information and support.

**Have modern methods of obtaining information (websites etc) affected your group/number of phone calls?** The numbers of people attending the support group and who contact me by telephone fluctuate. The availability of information on the internet means that a lot of, particularly younger, thyroid patients are very knowledgeable about the issues. This means that they sometimes come up with facts or figures that I am not acquainted with and so I have to check for myself, the information they provide. This can sometimes be challenging especially when they quote information from other thyroid patient website, but I can always contact BTF who will pass on queries to their excellent team of medical advisors.

**What do you most enjoy about volunteering for the BTF?** As a local coordinator the best part of the role is facilitating the local support group meetings. Most people who come along are really grateful for the chance to meet and chat to other thyroid patients as well as getting more information about their condition. Usually the meetings produce quite a lot of humour and laughter and nearly always end up on a positive note which is great for me as a coordinator and makes me feel that the BTF is continuing to make a worthwhile contribution to the needs and lives of the thyroid patients I deal with.
Putting thyroid tests into context: results from the Newcastle 85+ study

Professor Simon Pearce, Professor of Endocrinology, Institute of Genetic Medicine, Newcastle upon Tyne, outlines the results of a study he has been involved in that indicates there is no good reason to treat older people with slightly elevated TSH levels provided they are feeling OK.

He explains: Doctors often use information from studies of middle-aged people to make decisions about patients who are over 85, because there are very few studies involving much older people. During 2005 a project was started in Newcastle to find out as much as possible about the health and social circumstances of people over 85. More than 800 people who were born during 1921 agreed to be involved in the study and as well as hundreds of measurements including their body shape, physical state, cognitive tests, dental, lung and cardiac assessments, their thyroid blood tests results were also recorded. These people were followed up for nine years to find out what happened (when they were either 94 or deceased). The study excluded people already taking levothyroxine, and thyroid function test results were available on 643 people who provided enough health information.

Although there is some evidence that mild thyroid underactivity (with blood TSH in the 5 to 10 mU/l range) is associated with heart disease in younger people, the study showed no survival disadvantage to 85 year olds with high TSH. So this provides evidence that there is no good reason to treat older people with these modestly elevated TSH levels provided they are feeling OK. TSH is therefore different from cholesterol, where there is a lot of reflex prescribing, based on the blood test levels.

In addition, it is well known that when you become poorly for almost any reason (except thyroid over-activity) the blood FT3 levels go down and the ‘complementary’ thyroid hormone metabolite reverse T3 (rT3) goes up. In medical jargon this is sometimes called ‘sick-euthyroid syndrome’. The study confirmed that both lower FT3 and higher rT3 strongly predicted mortality.

The study also looked at whether thyroid test results could predict who would become disabled in the future. It turns out that:

- for men lower serum TSH predicted progressive disabilities, whereas for women reverse T3 was predictive
- interestingly, serum FT4 predicted neither mortality nor disability!

As people continue to live longer, we next need to do a study of 90 year olds.

Full details are available: Pearce et al. Serum thyroid function, mortality and disability in advanced old age: The Newcastle 85+ study. Journal of Clinical Endocrinology & Metabolism 2016;jc20161935. PMID: 27552542

BTF Research Award 2017

The BTF offers an annual award to support a one-year research project into thyroid function or thyroid disorders. This year’s award is up to £20,000 and has been funded by a legacy. The condition of the legacy is that the award should be used specifically for research to improve our understanding of hypothyroidism.

Applications for this year’s award are therefore invited specifically for research into assay and assessment of thyroid function with particular application to the diagnosis and management of hypothyroidism.

Full details and an application form are on the BTF website www.btf-thyroid.org/index.php/awards/research-awards

Deadline: 31 January 2017

Fight for Sight/BTF Small Grant Award winner 2014 Interim Report

Mr Daniel Ezra, Consultant Ophthalmologist at Moorfields Eye Hospital and lecturer at the UCL Institute of Ophthalmology has provided an interim report on his study on The application of 3D facial imaging system in the management of thyroid eye disease.

He explains: ‘A real challenge to the monitoring and management of patients with eye socket diseases is the limitation of conventional techniques to estimate changes in the volume of the tissues of the eye socket. Conventional techniques require ‘exophthalmometry’, which measures the protrusion of the cornea. However, this does not capture other changes in the upper and lower lids. We are using a 3D camera technology to more accurately assess this. We have completed the validation work and have also almost completed our patient recruitment. We expect to have published our studies on the application of this technology to real clinical scenarios in the coming months.’

Mr Ezra added: ‘We are very excited about the possibility of developing this new technology to be used to monitor orbital disease. In addition to improving disease management, it will also help us to understand how orbital disease progresses and how it responds to surgery’.
Thyroid and the eyes

Continuing on from previous features on how the thyroid affects many different parts of the body, here we look at how thyroid disorders can affect the eyes:

**What is thyroid eye disease?**
Thyroid eye disease is an ‘autoimmune’ condition. ‘Autoimmune’ means that your own white blood cells or antibodies are causing damage to parts of your own body in addition to their normal role of protecting you against infections. In the case of thyroid eye disease, the damage is directed to fatty tissue behind the eye. Swelling of the damaged tissues behind the eye can cause the eyes to become red and swelling to occur above and below the eyes. It may also cause the eyes to be pushed forward (‘starey eyes’, ‘proptosis’). In more severe cases, the damage at the back of the eye causes swelling and stiffness of the muscles that move the eye, causing double vision especially when you look from side to side, as the muscles cannot keep the eyes exactly in line with each other. Occasionally, the swelling behind the eyes is bad enough to press on the nerve from the eyes to the brain affecting your vision.

**What causes it?**
We do not know yet. One theory is that it follows infection with a virus that has molecules that look to the body very like the ones behind the eye. The body then makes antibodies and white cells to get rid of the virus but the reaction spills over onto the cells behind the eye. The body successfully removes the virus but is left with an ‘autoimmune’ reaction against the eye which continues. This remains just a theory as the virus, if there is one, has not yet been found. However, we do know that thyroid eye disease, as its name suggests, is closely connected with autoimmune thyroid disease and that it is more likely to happen in smokers. It has only a slight tendency to run in families.

**What are the most common symptoms?**
Mild soreness and grittiness of the eyes. (One eye is usually affected more than the other.) Increased watering of the eyes, a dislike of bright lights and a feeling of discomfort behind the eyes, especially when looking up or side-to-side. Puffiness of the upper eyelid or around the eyes (‘baggy eyes’) is also common (worst first thing in the morning). The eyes often appear ‘starey’ and dry or water too much which can cause blurry vision on and off.

**What is the connection with thyroid disease?**
In addition to the antibody or white cells that cause the eye problem, 90 per cent of people with thyroid eye disease also have an antibody in their blood that causes an over-active thyroid gland (Graves’ disease). The reason the autoimmune condition affects both the eyes and the thyroid seems to be that they share a common molecule, the TSH receptor. The eyes and thyroid are not always affected at the same time however. For example, the thyroid over-activity can come first and then the eye disease can develop even after the thyroid has been treated. Also, treatment of one does not treat the other. A small number of people who develop thyroid eye disease have no thyroid disturbance and some have an under-active thyroid.

**Will treatment for the thyroid make the eyes better or worse?**
In general, no, but uncontrolled over- or under-activity of the thyroid can make the eyes worse. Treatment of the thyroid over-activity with tablets or surgery rarely affects the eye. However, studies have suggested that radioactive iodine treatment for the thyroid may make the eye problems worse.

Since the eye and thyroid problems, although connected in some way, run their own separate courses, worsening of the eyes after thyroid treatment is often a coincidence rather than a direct effect of the thyroid treatment. Nonetheless, it is strongly recommended that patients with active eye disease avoid radioactive treatment. A large study (PRAGMA) is currently underway, led by BTF Trustee Dr Petros Perros to establish the best treatment pathway for those with Graves’ disease and in particular TED.

**Radioiodine is safe for patients with active eye disease if given together with a short course of steroids.

Treatment for the thyroid may also affect the eyes in one other way: if the thyroid is over-treated and the thyroid becomes under-active (hypothyroid) this can worsen any eye problems.

**Can thyroid eye disease be prevented?**
To some extent. Giving up smoking and careful checks of thyroid blood level to avoid under-activity may help prevent the eye problems from getting worse although they are not the full answer. Also it has been shown that in patients with mild, active thyroid eye disease, a six month course of selenium supplements (200 mcg daily) can prevent deterioration.

**TED and quality of life?**
Doctors are increasingly aware that TED can have a huge impact on a person’s psychological and social well-being. Fluctuating thyroid levels make people feel anxious and/or irritable and suffer from mood swings. Anger, loss of self-esteem or confidence, or social isolation, because of the change in the appearance of the eyes is also common. An abstract produced by the award winning Thyroid Eye Disease Amsterdam Declaration Implementation Group (TEAMeD), an organisation set up to improve the treatment and outcomes of patients with TED, of which BTF is a founding member, reported that one of the highest priorities for future research was for psychological support. See www.ncbi.nlm.nih.gov/pubmed/26359308 Treatment - including surgery - can often improve the appearance of eyes; and counselling, or contact with fellow TED sufferers, can help people find coping strategies. See the BTF website or www.teduct.org.uk

**Three things to help if you have TED:**
*If you are smoker, give it up - ask your GP for advice or enrol on a quit-smoking programme. Patients with TED who carry on smoking respond less well to treatments, but this disadvantage seems to disappear soon after giving up smoking. Also non-smokers or ex-smokers are more likely to be cured of their thyroid over-activity after a course of Carbimazole (CMZ) or Propylthiouracil (PTU) treatment, than smokers. See www.btf-thyroid.org/projects/teamed/235-ted-and-smoking-information-for-patients

*Avoid fluctuations in your thyroid levels - have thyroid blood tests regularly, and follow the advice given by your doctor about when and how to take your medication so your thyroid levels remain steady. This will give your eyes the best chance of healing and improve the way you feel.

*Selenium supplements - evidence suggests that patients with mild active TED may benefit from a six month course of over-the-counter selenium supplements at a dose of 100mcg twice daily.

**Future treatments?**
Clinical trials have been performed in search of different ‘immune modulating’ drugs (modification of the immune response or the functioning of the immune system by the action of an immunomodulator (drug)) including steroids and Rituximab (see BTF News 92 page 5). These studies have resulted in much improved management of the moderate to severe forms of Graves’ Orbitopathy (GO). The results of three trials exploring the use of Mycophenolate, Tocilizumab, and Teprotumumab in thyroid eye disease are also imminent. The work of The European Group on Graves’ Orbitopathy (EUGOGO) and Thyroid Eye Disease Amsterdam Declaration Implementation Group (TEAMeD) has improved the speed of diagnosis and trials targeting the causes of Graves’ disease such as INDIGO (see BTF News 90 page 11) will hopefully lead to new treatments to manage TED better in the future.

**References**
http://www.british-thyroid-association.org/info-for-patients/Docs/ptinfo-TED.pdf
http://www.btf-thyroid.org/information/leaflets/36-thyroid-eye-disease-guide
Gillian describes her experience of TED:
I was diagnosed with an over-active thyroid in November 2000, although it did take quite some months for this to be diagnosed, even though I had most of the symptoms. As I was a busy working mum, I was told I must be overdoing things and to just take things a little easier. I went on to develop swollen ankles, however, my GP then said I must have pulled muscles in both my legs. I knew this was not the case and returned to see her the following day with no appointment, but insisted I saw her as I was feeling so ill. I told her I knew I’d not pulled muscles in my legs and that something was very wrong. She then referred me to hospital for some tests and I was diagnosed with an over-active thyroid and treated with levothyroxine and Carbimazole for 12-18 months until it became stable. (My swollen ankles were due to my over-active thyroid not being treated and it had started to affect my heart.) Two years later, I became over-active again and felt pretty awful once again. This time I was treated with radioiodine with the intention of killing off my thyroid altogether. Within a few days of having this treatment my energy levels returned and I felt much better.

Six weeks after the radioiodine treatment, I got up one morning to find my eyes very swollen underneath. This was the start of my TED journey. My eyes became very sore, red and watery. They were sensitive to bright lights and my eyes had started to protrude out and I had a starey look. I found this very distressing. I was prescribed the steroid prednisolone for six months and then in 2007 after the disease burnt out, I had surgery twice. I was very pleased with the results.

I am currently on 87.5mcg of levothyroxine (100mcg and 75mcg alternate days) to stabilise my condition and have blood tests usually every three months. My thyroid levels fluctuated somewhat during 2013-2015 which mystified my GP, however, I was suffering from a lot of stress at that time. Things have thankfully improved and my levels for the last six months or so have been normal.

Orthoptists themselves have developed their role dramatically over the years. From once being at the end of the queue waiting for referrals they are now autonomous practitioners, receiving referrals directly from both external and internal departments and refer patients on to relevant departments after initial assessment. They are often the first point of contact for a patient with diplopia and this may be the first sign of TED and therefore good communications between relevant departments is vital so that patients can receive early treatment. We also have an important role to play in health education, particularly with helping to stop smoking.

I have been lucky enough to work in Leeds for 35 years and as part of a specialist team since 2009. We have changed our practice during this time to meet the needs of patients, moving from one clinic per month to two in order to offer a better quality service. The team consists of consultant endocrinologist, ophthalmologist and orthoptist. Patients will see one, two or all of us depending on the nature or severity of their symptoms and I triage all new patients so they have a baseline of their eye signs in case of change later on.

Patients are made to feel part of the team. They still make regular visits but they are better informed as to what their management plan is likely to be, rather than the ‘wait and see what happens’ approach of the past. In a personal reflection of my career I would say that better communications between medical and allied health professionals has significantly changed the way that patients with TED is managed. Secondly, including the patient in discussions about their condition and management is a major step forwards from three decades ago. Both time and good communications are valuable resources often under threat, but both need to be nurtured for the well-being of our patients.
Rachael explains what a shock it was to be diagnosed with an under-active thyroid just as she discovered she was pregnant and how grateful she was for a quick diagnosis.

In May 2012 I booked an appointment to see my GP because I just didn’t feel ‘right’. My husband and I had two beautiful, healthy children, aged two and nearly four, but we had always dreamed of having a third and we had been trying for our number three for the previous year and a half. In that time, I had been pregnant and miscarried twice, which had been devastating for us. I had no problems conceiving my first two children and had few problems during those pregnancies, so it hit hard when it was proving difficult to complete our family (or so it felt to us).

I explained to the doctor that since the second miscarriage, my periods had become progressively heavy, to the point that on my last period I was noticeably pale and had nearly fainted several times. This was not at all normal for me and I felt it either needed investigating or I needed reassurance that I was OK. The doctor was very understanding and she suggested that I have some general blood tests to check my hormone levels.

A couple of days later, however, I received a phone call from the surgery to tell me that my blood tests had come back and that these showed me to have an under-active thyroid and that I needed to start on medication. I was told to stop trying to conceive until my levels were back to normal as it could harm the baby. I asked if this could be why I had miscarried and the doctor thought it was highly likely, although we could never know for certain. The doctor arranged for me to have a repeat blood test to confirm the results and for a prescription of levothyroxine to be available for me to collect.

It came as such a shock to me that I had such a condition, as I really hadn’t shown any other symptoms. Over the phone, the doctor had asked me if I was tired, but all I could think was ‘yes, but I have a two- and three-year-old at home!’ and I honestly couldn’t say I was any more tired than my other mummy friends.

However, I got an even bigger shock when, just a couple of days later, I found out I was already pregnant! This, clearly, should have been the best news, but it suddenly felt like the worst, and I thought that I was going to have to go through another miscarriage, just when everything was starting to look more positive. I booked an urgent appointment at the doctor’s and the following week was a whirlwind of appointments and phone calls. It was arranged for me to see the Consultant Endocrinologist at the hospital as soon as possible. He agreed that my medication should be quickly increased, for the sake of the baby, and that I would be monitored throughout my pregnancy. It was a very stressful time but I finally saw the smallest glimmer of hope when he told me that there was no reason, because the hypothyroidism had been caught early in the pregnancy, I should not have a healthy baby. I burst into tears with the relief!

I didn’t let myself fully believe that our number three would actually arrive but our little boy, Patrick, was born in February 2013 and he could not have been more perfect – 8lb 6oz of bouncing baby boy who is now three and a half and about to start pre-school. There are no words to express how grateful we are to the doctor who first arranged my blood tests, as I am certain that without her actions, our Patch would not be here today. I am just sad that it was not detected earlier and I hate the thought that other women could be going through the same situation, leading them to give up hope of ever having a child. I now know that both my grandmothers had under-active thyroids and my mum has in recent years developed hyperthyroidism but it hadn’t occurred to me that this could affect me at some point as so little is known in the general public about thyroid disorders and how they can affect so many lives.

This is why I decided to run this year’s York 10k in aid of the BTF; to raise funds and awareness, in the hope that sharing my story may help someone get their happy ending too.
Some small studies have reported a positive association between autoimmune thyroid disease and glaucoma (raised eye pressure) but these have not been confirmed in large population studies, particularly after other risk factors such as age, gender and other conditions have been taken into account. However, our medical advisor replies: Where there is some indication of a link between thyroid disorders and eye pressures?"}

**Slow increase of levothyroxine dose**

**CH asks:** I am a GP and I have recently been diagnosed with hypothyroidism. I was started on 25mcg levothyroxine four weeks ago and then increased to 50mcg three weeks ago. I am still symptomatic, tingling in my hand and leg, tiredness, muscle aches and inability to walk any distance. I am also cognitively slower.

I was wondering why there is such a slow progress in medication doses? Intuitively, from inside, I want to get better as quickly as possible. Although I feel better I also feel there is a way to go and do not understand why I have to remain unwell for longer while slowly increasing doses of levothyroxine. I have been on work but am returning tomorrow and know it will be very hard work. Apart from the cardiovascular risk and the difficulty in predicting precisely the right dose because of the delay in TSH changes there does not appear to be any reason not to go fairly quickly to 100mcg or 150mcg (recommended in The Oxford Handbook of General Practice).

I wonder if you could advise? What I would like to do is jump to 100mcg then monitor in six weeks rather than wait another three weeks at 50mcg.

**Our medical advisor replies:** The expected dose of levothyroxine is 0.8-1.6mcg per kg per day. So for a 75kg individual this is about 60-120mcg daily. Patients started on full replacement doses suffer no adverse effects provided they do not have cardiovascular problems and are not over 70 years old. It is perfectly acceptable to go directly to 100mcg of levothyroxine depending on the patient’s weight. Starting with small doses is only recommended in patients who are elderly or those who have cardiac problems.

**Correspondence**

**CM asks:** I was hoping you could help me please as I am very worried about my daughter who was diagnosed with an underactive thyroid towards the end of last year. She is 21 years old and was put onto levothyroxine right away. She says initially it made her feel better but the effects soon wore off. Her dosage was increased to 75mcg per day but she then admitted there were times when she forgot to take them. Having been on and off the tablets since then she told me last night that she gets very low moods and sleeps nearly every day down to 3pm or 4pm. When she compares how she feels to before she started taking medication she says she actually feels a lot worse now and on numerous occasions has had thoughts of not wanting to be here. She has assured me she has never tried to harm herself but her low moods and constant fatigue are taking over her life and I am really worried for her. She has told me she doesn’t want to spend the rest of her life on tablets and I am concerned about how she is going to manage her condition.

**Our medical advisor replies:** Thank you very much for your email. I am sorry to hear your daughter hasn’t been feeling well. Unfortunately it can sometimes take several months to find the right dose of levothyroxine and it may be that your daughter isn’t yet getting the correct amount and therefore is still experiencing the common symptoms of hypothyroidism. www.btf-thyroid.org/information/leaflets/29-hypothyroidism-guide and www.btf-thyroid.org/information/leaflets/37-psychological-symptoms-guide

**Letters and Comments**

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

Please address general letters to: The Editor, BTF News, The British Thyroid Foundation Suite 12, One Sceptre House, Hornbeam Square North, Hornbeam Park, Harrogate HG2 8PB or by email to editorialboard@btf-thyroid.org

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

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

**Link between thyroid disorders and eye pressures?**

**NM asks:** I have just had the results of some thyroid blood tests that show raised antibodies and I have also had an eye check which shows raised pressures, mostly in my right eye - although thankfully the eyes are healthy otherwise. Is there a correlation between thyroid disorders and raised eye pressures?

**Our medical advisor replies:** There has been no robust association between autoimmune thyroid disease and glaucoma (raised eye pressure) noted in the scientific literature. Some small studies have reported a positive association between self-reported hypothyroidism and glaucoma but these have not been confirmed in large population studies, particularly after other risk factors such as age, gender and other conditions have been taken into account.

**Magnesium supplements**

**KG asks:** I am having terrible trouble sleeping and it’s beginning to affect my whole life. I can’t concentrate at work and feel drained and irritable all the time. I am also menopausal and suffer with terrible night sweats. Someone has recommended I take magnesium supplements as they said since they had taken them they are sleeping like a baby, however I take 125mcg of levothyroxine every day as I had a full thyroidectomy about seven years ago and I also had orbital decompression surgery for Graves’ disease. Can you please advise if I am able to take magnesium supplements? I know not to take any other medication for four hours after my levothyroxine but I just need to know if I can take magnesium at all?

**Our medical advisor replies:** Magnesium supplements should be taken four or more hours after levothyroxine (just like calcium) but there should be no problem otherwise.

**Correct dosage?**

**CH asks:** I was hoping you could help me please as I am very worried about my daughter who was diagnosed with an underactive thyroid towards the end of last year. She is 21 years old and was put onto levothyroxine right away. She says initially it made her feel better but the effects soon wore off. Her dosage was increased to 75mcg per day but she then admitted there were times when she forgot to take them. Having been on and off the tablets since then she told me last night that she gets very low moods and sleeps nearly every day down to 3pm or 4pm. When she compares how she feels to before she started taking medication she says she actually feels a lot worse now and on numerous occasions has had thoughts of not wanting to be here. She has assured me she has never tried to harm herself but her low moods and constant fatigue are taking over her life and I am really worried for her. She has told me she doesn’t want to spend the rest of her life on tablets and I am concerned about how she is going to manage her condition.

**Our medical advisor replies:** Thank you very much for your email. I am sorry to hear your daughter hasn’t been feeling well. Unfortunately it can sometimes take several months to find the right dose of levothyroxine and it may be that your daughter isn’t yet getting the correct amount and therefore is still experiencing the common symptoms of hypothyroidism. www.btf-thyroid.org/information/leaflets/29-hypothyroidism-guide and www.btf-thyroid.org/information/leaflets/37-psychological-symptoms-guide

**The correct dose of levothyroxine is one that restores good health. In most patients this will be associated with a TSH reading in the lower half of the reference range and a T4 in the blood towards the upper part or even slightly above the reference range. Please see our information leaflet and thyroid function tests for further details. http://www.btf-thyroid.org/information/leaflets/34-thyroid-function-tests-guide It is also very important that she takes her...**
Continued from page 13

tablet each day. They are best taken on an empty stomach, at least an hour before eating and drinking anything. Sometimes people find it more convenient to remember to take their tablet last thing at night so she may find that helps. If she doesn’t take them regularly there will be an effect on her health and the blood test results.

I suggest she makes an appointment to see her doctor to discuss the way she is feeling and if appropriate to get up to date blood tests. The doctor will hopefully be able to help her understand the importance of levothyroxine, why she needs to take it, and also devise a strategy to help her take them consistently.

It may also be useful for her to speak to one of our telephone contacts. http://www.btf-thyroid.org/resources/131-telephone-support

For children with a thyroid condition and their parents/carers

Central thyroid problem

SH asks: Hello, my two year old son has just been diagnosed with central hypothyroidism

and I am trying to find out as much information as I can and understand what it is, why or how he may have developed it and how is it different from a thyroid disorder, i.e. the more common thyroid problem. I'd also like to know what to expect for the future for my boy as he grows. I will be speaking to my own doctor but know how busy they are so want to find out as much as I can before I see him.

Our medical advisor replies: Central hypothyroidism is indeed a rare problem and I think it is very important that you sit down with your local paediatric endocrinology team and talk through the diagnosis and its management in detail. They may be busy professionals but this is their job and I am sure they will be happy to do this. You might want to suggest meeting ‘outside’ of normal clinic hours so that there is more time to hand.

There are important differences between primary and secondary hypothyroidism as you suggest but the local team should be able to discuss these with you and make sure that you become an expert too!

We also have a closed Facebook group for parents of children with thyroid disorders that you might wish to join - just let us know.

Ed

MC asks: Hi, my daughter has just been diagnosed with a multi-nodular goitre. She is 10 years of age and I am trying to research any information I can on this. I have found great comfort in reading your webpage, and would like to join your Facebook page.

Our medical advisor replies: There are different causes of a multi-nodular goitre. Ask your local paediatric endocrinology team to talk through the diagnosis and its management in detail with you.

Multi-nodular goitres are uncommon in the young. Most (but not all) do not result in abnormal thyroid hormone production. They tend to be a ‘nuisance’ condition that can sometimes require longer term follow-up – however the condition doesn’t usually affect general health in any major way which is good news. The problem for some young people is simply having a lumpy thyroid gland in your neck that can make people a bit self-conscious if it is on the bigger side.

For children with a thyroid condition and their parents/carers

Multi-nodular goitre

MULTI-NODULAR GOITRE

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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 of £250,000 or less.

You can leave a legacy to the BTF in your Will or during your lifetime, for example by donating through a living trust. Any gift, large or small, makes a real difference. A legacy can take many forms – you might wish to leave a cash legacy, a bequest of a house or car, a gift of shares, or a specific asset such as a work of art. If you have any questions about leaving a legacy to the BTF please contact our Legacy officer Emma Winter. Email legacies@btf-thyroid.org or call 01423 810093.

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 are 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 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

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

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.
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: Saturday 22 October 2016
2pm to 4pm
Location: Yardley Baptist Church, Rowlands Road, South Yardley, B26 1AT, off the A45 Coventry Road. Free parking available.
Programme: The guest speaker will be Mr Neil Sharma, NIHR Clinical Lecturer and Specialist Registrar in Otolaryngology, Head and Neck Surgery, The University of Birmingham. He will be presenting information about the new research proposal STRATIFII which is a trial of patients with thyroid cancer who are receiving radio iodine ablation. There will also be an overview of thyroid, head and neck surgery including an opportunity for questions and answers.
Come along to find out more!
Do you need advice about how to cover and conceal scars and blemishes? Get tips from our makeup demonstrators for everyday use or maybe just for a special occasion.
Donation: £2 voluntary donation.
Contact: Janet Tel: 0121 628 7435 or email: janetdmp@googlemail.com

Leeds (Wharfedale)
Next meeting: Come along to our Christmas Social on Wednesday 7 December at 7.30pm (ish)
Location: The Deer Park Hotel, Street Lane, Leeds, LS8 2DQ
All Welcome. Bring a friend along if you like. Make new contacts, share stories, experiences, have a moan and a laugh! Raffle Proceeds to the BTF (please bring a prize to donate)
Contact: Caroline on 0113 288 6393 or email: cfields237@btinternet.com

London
Next meeting: 26 November 2016 10am to 1pm.
Location: Crown Court Church, Russell Street, Covent Garden, London WC2B 5EZ
http://www.crowncourtchurch.org.uk/where-to-find-us/
Programme: This will be a support group meeting. In order to continue the group meeting needs more volunteers to help run it - if anyone is interested in helping or attending a meeting email info@btf-thyroid.org

Bristol
Welcome to Michelle who is forming a new group in Bristol. Email her at Michelle.Griffiths@hotmail.co.uk if you would like more information.

Cambridge
Next meeting: 12 November 2016 10am for 10.30am start to 1pm
Location: Weston Colville Reading Room CB21 5NX. Several members of the group have offered lifts from Linton to Weston Colville. There is a good bus service from Cambridge to Linton.
Programme: Support meeting
Donation: £4 voluntary donation
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: Come along to our Christmas Social on Wednesday 7 December at 7.30pm (ish)
Location: The Deer Park Hotel, Street Lane, Leeds, LS8 2DQ
All Welcome. Bring a friend along if you like. Make new contacts, share stories, experiences, have a moan and a laugh! Raffle Proceeds to the BTF (please bring a prize to donate)
Contact: Caroline on 0113 288 6393 or email: cfields237@btinternet.com

Birmingham
Next meeting: Saturday 22 October 2016
2pm to 4pm
Location: Yardley Baptist Church, Rowlands Road, South Yardley, B26 1AT, off the A45 Coventry Road. Free parking available.
Programme: The guest speaker will be Mr Neil Sharma, NIHR Clinical Lecturer and Specialist Registrar in Otolaryngology, Head and Neck Surgery, The University of Birmingham. He will be presenting information about the new research proposal STRATIFII which is a trial of patients with thyroid cancer who are receiving radio iodine ablation. There will also be an overview of thyroid, head and neck surgery including an opportunity for questions and answers.
Come along to find out more!
Do you need advice about how to cover and conceal scars and blemishes? Get tips from our makeup demonstrators for everyday use or maybe just for a special occasion.
Donation: £2 voluntary donation.
Contact: Janet Tel: 0121 628 7435 or email: janetdmp@googlemail.com

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Contact: Caroline on 0113 288 6393 or email: cfields237@btinternet.com

London
Next meeting: 26 November 2016 10am to 1pm.
Location: Crown Court Church, Russell Street, Covent Garden, London WC2B 5EZ
http://www.crowncourtchurch.org.uk/where-to-find-us/
Programme: This will be a support group meeting. In order to continue the group meeting needs more volunteers to help run it - if anyone is interested in helping or attending a meeting email info@btf-thyroid.org

Bristol
Welcome to Michelle who is forming a new group in Bristol. Email her at Michelle.Griffiths@hotmail.co.uk if you would like more information.

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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.

Shop online and raise money! easyfundraising
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, 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?
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.

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.
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)
janetdmp@googlemail.com
0121 6287435

Cambridge Mary (O,Ri,U)
butterflyecho@hotmail.com
01223 290263

Edinburgh Margaret (PC)
0131 6647223

Leeds (Wharfedale) Caroline (O,U)
0113 2886393

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 (PC,CS,RAI) 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
María (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

- 6pm to 8pm weekdays
- 2 to 5pm Monday, Tuesday and Thursday
- After 6pm weekdays and anytime weekends
- 9am to 5pm weekdays, 10am to 5pm 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 516076 www.amend.org.uk

Hypopara UK Helpline: 01342 316315 www.hypopara.org.uk

Thyroid Cancer Support Group Wales Tel: 08450 092737
www.thyroidsupportwales.co.uk

Thyroid Cancer Support Group Ireland www.thyroidcancersupport.ie
email info@thyroidcancersupport.ie

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

Cancer52 www.cancer52.org.uk

Thyroid Eye Disease Charitable Trust Tel: 07469 921782
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

Members living in the UK
By cheque
Full: £25 per year
Concession: £15 per year
By standing order
Full: £25 per year
Concession: £15 per year
Lifetime membership
£200 by cheque

Members living overseas £25 Europe (electronic newsletter only)
By cheque from a UK bank account
By standing order through a UK Bank
By sterling bank draft drawn on a UK Bank

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

Order your BTF Christmas cards

We have a great collection of contemporary and traditional Christmas cards that we are selling to raise funds for the BTF. We would be very grateful for your support. You can order your Christmas cards cards now by filling in the flyer enclosed with this newsletter or by visiting the BTF website: www.btf-thyroid.org.

The British Thyroid Foundation, Suite 12, One Sceptre House, Hornbeam Square North, Hornbeam Park, Harrogate HG2 8PB
Tel: 01423 810093 www.btf-thyroid.org Office enquiry line open: Mon - Thurs: 11am-2pm.