BTF HOSTS FIRST EVER CONFERENCE FOR CHILDREN WITH THYROID DISORDERS

When the day came for the BTF’s first Children’s Conference after months of planning it was a not-to-be-missed opportunity for over 25 families. Parents made the journey from all over the UK, and two families came especially from Ireland and France.

While the children were entertained by BTF staff and volunteers (led by our wonderful Notts/Derby local coordinator Bridget O’Connor) the parents learned about thyroid disease, how it can affect their children and how to deal with a long term health condition.

Several endocrine specialists from Leeds General Infirmary (Dr Ramzi Ajjan, Dr Sabah Alvi, Dr Talat Mushtaq, Sister Amanda Whitehead and Sister Jenny Walker) made presentations, led workshops and were available to answer questions throughout the day. There were very helpful and positive talks by teenagers Katy Lestner and Hannah Savage on how they have coped with their thyroid condition and not let it rule their lives. Also a parent’s perspective was presented and discussed by mums Joanne Lestner and Georgina Hudson-Croker.

Emma Boon, who came with her eight year old daughter Chloe said ‘We had a lovely day and Chloe had the chance to realise that she wasn’t the only one with a dodgy thyroid. That was the main reason for us to attend, to make her aware of others just like her. She said on the train on the way home ‘This has been the best day ever!’ and was so pleased when she got ready for bed because she realised that she already had butterfly lights and a lampshade, and has now added to that with the things she made at the meeting.’

Another parent told us that the aspect of the day she most enjoyed was the chance to meet other parents. ‘I feel that seven years of worry about my child were lifted from my shoulders as everyone seemed to have very similar experiences and reactions.’

Julia Priestley, BTF’s Development Officer who organised the conference said ‘We were delighted that so many families were able to come to the meeting and it was truly wonderful to have helped give parents the opportunity to learn so much from the LGI team and each other.’

Parent Georgina Hudson-Croker with son Oliver

Chloe Boon

Parent’s feedback session

BTF volunteer Helen with the budding medics!
Welcome to…

Dr Mark Strachan, a current BTF Trustee who has become BTF Treasurer. Mark has been a Trustee with the BTF since 2009. He is a Consultant in Diabetes and Endocrinology, Western General Hospital in Edinburgh and a Reader in Medicine at the University of Edinburgh.

Mr Dan Ezra who is a Consultant Ophthalmologist at Moorfields Eye Hospital and lecturer at the UCL Institute of Ophthalmology, specialising in oculoplastics and orbital disease. He is also the Clinical Trials Lead and Training Director for adnexal surgery.

Dr Peter Taylor who is a Clinical Academic Trainee in Diabetes and Endocrinology currently undertaking his PhD at Cardiff University having also trained in epidemiology (the science of the patterns, causes, and effects of health and disease).

Professor Simon Pearce, who is Professor of Endocrinology, Newcastle University. His studies range from laboratory based DNA analysis to clinical trials of new therapies.

Dr Mark Vanderpump, Consultant Physician and Honorary Senior Lecturer in Diabetes and Endocrinology at the Royal Free Hampstead NHS Trust in London. He has published on various aspects of thyroid disease and served on the Executive Committee of the British Thyroid Association (BTA) between 2002 and 2008. He was elected President of the BTA in April 2014. (see page 10).

Further members of the Editorial Board are:

Liz Clegg who has worked at BTF HQ for the last two years coordinating the BTF newsletter, fundraising and BTF research award. She previously worked for a business publishers in Manchester and in the corporate communications department of Experian.

Nikki Brady who has volunteered for BTF HQ since 2010, providing on-going support for the production of the newsletter. Nikki trained as a journalist before working as a reporter on a regional newspaper. She is now a member of the communications team at Yorkshire Cancer Research, managing the charity’s PR activity.

Our new trustee Bridget O’Connor, Bridget has been the BTF Notts/Derby local coordinator for seven years after being diagnosed with Graves’ disease. She is also a telephone helpline contact for the BTF and Hypopara UK and actively fundraises for both charities. She works closely with local endocrinologists regarding awareness meetings and will be able to provide a valuable viewpoint from both a patient’s perspective and the community.

BTF News editorial board

Working with BTF HQ this group of medics will be advising and contributing to BTF News, providing input for the medical and research sections of the newsletter. They are:

Dr Petros Perros who is a Consultant Endocrinologist at the Royal Victoria Infirmary, Newcastle, an Honorary Senior Lecturer, Institute of Genetic Medicine, Newcastle University, a previous trustee of BTF, medical advisor and medical editor of the BTF newsletter, member of TEAMeD, President of the European Group on Graves’ Orbitopathy and Chairman of the British Thyroid Association Thyroid Cancer Guidelines Group.)

Farewell to…

David Fortune who has resigned as a BTF volunteer and BTF trustee due to increasing commitments. David has been an invaluable help, answering medical queries and project managing the implementation of a quality management system at BTF HQ.

Judith Taylor who has stepped down as editor of the BTF News, a voluntary position she held since 2009. Judith, who has a specific interest in thyroid cancer, wrote many articles for BTF News, including updates about what was happening in the scientific community worldwide.

Lorraine Williams who has stepped down as Coordinator of the BTF London Group due to other commitments. Lorraine created a very active and thriving group in London. The role has now been taken on by Denise Sims (see page 15).

Our thanks to David, Judith and Lorraine for their support over the years.

Thyroid Awareness Week

25 – 31 May 2014 was the sixth International Thyroid Awareness Week and the BTF partnered with its international counterparts to raise awareness of thyroid disorders. This year the focus was on ‘Five reasons to be aware of thyroid disease’: thyroid cancer, auto-immune disease, infertility (see page 10), depression/anxiety and iodine deficiency (see page 5). The BTF issued a press release on infertility to coincide with this week and to highlight this important issue.

A special website has been set up with further information on these five issues: go to www.thyroidweek.com

Helping deaf people access health services

BTF has worked with Sign Health, the deaf people’s charity to prepare the text to be used in the British Sign Language video clips on hyper- and hypothyroidism. Sign Health launched their Sick Of It report in April to highlight the difficulties deaf people face in the health service. Go to www.sick-of-it.com for more information.
Raising awareness about hypothyroidism at GP surgeries

A specially designed poster and leaflet raising awareness of hypothyroidism has been placed in 750 GP surgeries in England. The company who has carried out the placements, IDS UK, is a specialist in providing healthcare communication solutions across health care environments and has provided this service free of charge to the BTF.

What would you like to see in your newsletter?

Let us know what you would like to read about in BTF News. What do you find the most interesting and what would you like to see more (or less) of? Members’ views are important to us and we welcome feedback. Email editorialboard@btf-thyroid.org with any suggestions or comments.

Carrots NightWalks

There is still time to sign up to take part in one of the national night walks organised by Fight for Sight. This year’s Carrots Nightwalks will take place in September. You can join up to walk in one of five UK cities: London (19 September), Birmingham, Bristol (26 September) and Glasgow (27 September).

If you are interested in raising money for research into thyroid eye disease and would like to take part in this fantastic event please email j.hickey@btf-thyroid.org stating the city you would like to walk in.

Email addresses

We would really like to be able to keep in touch with members electronically. We do have some members’ email addresses but if you joined before 2013 please send your name, email address, postcode and house number to info@btf-thyroid.org and use the subject ‘Member’s email address’.

Leave a legacy to the BTF

Help to make a real difference by remembering BTF in your Will. Any gift, large or small, makes a real difference. Legacy donations allow us to continue providing life-changing support to people with thyroid disorders. If you do decide to remember BTF in your Will, your gift will mean that BTF will still be here for people who need our support in years to come. By leaving a legacy you can take advantage of the reduced rate of inheritance tax of 36% (previously 40%) that came into effect from April 2012 for estates leaving a legacy to charity. Call 01423 709707 or email legacies@btf-thyroid.org for an information pack.

OUT AND ABOUT

Thyroid eye disease in the 21st century

Newcastle upon Tyne – a centre of excellence for thyroid eye disease (TED) – hosted a two-day event in May that brought together leading European and British experts on TED.

The event provided a unique opportunity for patients with TED, their families and carers, and members of the public to meet with the experts to find out about the latest advances and together be involved in discussions about the priorities for future research into TED. Six patient representatives with TED were involved, including Janis Hickey and Peter Foley from the BTF, Gillian Barron and Sue Devine from TEDct, Sian Gray, a GP, and Peter Howe, who had been treated in Newcastle for TED. Two Thyroid Federation International (TFI) members made the journey to be involved in the event: Beate Bartes, Founder/Director of Vivre sans Thyroïde, France, and Dr Nancy Hord Patterson, who developed TED in 1987 and is founder of The Graves’ Disease Foundation in the USA.

Talks included discussions about the unmet needs of patients with thyroid eye disease in which the patient representatives talked about the struggles they had faced and highlighted the improvements needed.

This was followed by a lively discussion involving medical professionals and patients in the audience. Medical professionals acknowledged patients’ contributions to the success of the event and expressed concern over many aspects of information shared by patients.

The event was an opportunity for TEAMeD (Thyroid Eye Disease Amsterdam Implementation Group UK), of which BTF and TEDct are members, to distribute its Executive Summary Report, highlighting the work it has undertaken on TED since 2010 (see http://www.btf-thyroid.org/index.php/campaigns/teamed).

Continued on page 4
In a session chaired by BTF Trustee Professor Geoffrey E Rose, Janis Hickey, Dr Petros Perros and Professor Colin Dayan, all members of TEAMeD, gave separate presentations on the benefits and disadvantages of local/tertiary centres.

Day two comprised a seminar ‘Of Eyes, Mice and Dice’ sponsored by the Society for Endocrinology in which presentations took place from leading UK and European researchers on recent advances in finding out what causes the development of TED; how it is assessed and the latest treatments, providing an insight into the fascinating studies that are taking place.

On both days break-out sessions took place. In 2012 priorities for TED research had been set in the Sight Loss and Vision Priority Setting Partnership, in which Janis Hickey, Peter Foley and Mr Dan Ezra, Consultant Ophthalmic and Oculoplastic Surgeon at Moorfields Eye Hospital and member of TEAMeD had participated (see BTF News 82). These priorities were discussed in a breakout session on day one, the remit being to translate the priorities into specific research questions. On day two the break-out sessions involved translating the research questions formulated on the previous day into study designs.

The meeting was a joint venture between the European Group on Graves’ Orbitopathy (EUGOGO) and TEAMeD UK. Feedback about the event has been positive with participants saying how helpful they had found the sharing of information to be. One of the outcomes was the formulation of six major potential study proposals for basic and clinical research in this field, some of which will hopefully be taken further. There was a great sense of teamwork throughout the meeting and a desire for patients and professionals to build on the Newcastle experience and continue to work together.

In his closing remarks, Dr Perros thanked in particular the patient representatives for attending and said their involvement had greatly enhanced the quality of discussions. Janis Hickey, a member of the event organising committee, said, ‘We have Dr Perros to thank for his vision that patients with TED can make a positive contribution to such events. Working together with medical professionals and researchers to take matters forward and bring about improvements is a big step in the right direction. We are very grateful to Dr Perros for including us’.

British Endocrine Societies conference

The BTF attended the annual British Endocrine Societies (BES) conference from 24-27 March which was this year hosted in Liverpool.

This annual conference is the largest UK meeting on hormone research. It includes some of the best of British and international science and research, clinical investigation and clinical practice in endocrinology.

Medical and health professionals, clinicians and researchers converged on the spectacular Liverpool waterfront ACC conference centre for four days of presentations, debates, and workshops on the latest research and findings in the field of endocrinology. There was also an area for patient support group stands where the BTF was invited to exhibit. Julia Priestley from BTF HQ attended a meeting for patient support groups hosted by the Society for Endocrinology (SfE). She said ‘It was a valuable opportunity for the BTF to share ideas and best practice with other patient support groups throughout the UK and a chance to let the SfE know how best they can support the work the BTF does’.

There were a number of lectures on thyroid related issues. Highlights included a presentation by Peter Taylor (University of Cardiff) on the link between thyroid hormones and IQ in children (see ‘Research in the media’ page 9). Dr Taylor was also highly commended in the SfE’s Young Endocrinologists Clinical Oral Communications Awards for his presentation.

The BTF supported a session on ‘The emerging clinical importance of iodine.’ This session included a presentation by Professor Margaret Rayman (University of Surrey) on iodine nutrition and neurodevelopment and how inadequate iodine intake by pregnant women adversely affects cognitive outcomes in their children. She explained how iodine is a key component of thyroid hormones, which are crucial for brain development particularly in early years. The lecture was based on the results of the study, by Professor Rayman and Dr Bath (University of Surrey) and colleagues at the University of Bristol, which was published in The Lancet in May 2013. The study measured iodine status in pregnant women from the Avon Longitudinal Study of Parents and Children (ALSPAC) and found that low iodine status was linked to poorer IQ and reading ability in the child up to nine years.
Professor Rayman talked about the importance of adequate iodine status during early pregnancy and highlighted the risk that even mild-to-moderate iodine deficiency can pose to the developing infant. She stressed the urgent need for this issue to be addressed through public health initiatives.

Mr Daniel Ezra (Moorfields Eye Hospital) gave a lecture on thyroid eye disease (TED). The varied presentation of patients with TED was emphasised with special attention drawn to the different clinical features of the condition and how they can be practically assessed. Excerpts from the ‘patient panel’ at a recent national TED day held in London last year were also presented to stress how deeply this condition affects patients and why it is important to ensure that the condition is picked up early and referred on appropriately.

Professor Krishna Chatterjee (University of Cambridge) gave the annual British Thyroid Association Pitt-Rivers Lecture on genetic insights into disorders of thyroid hormone action. He explained that it is now recognised that the action of thyroid hormone can be regulated at several levels, including uptake of thyroid hormone into cells, its conversion (T4 to T3) within cells and its action in the cell nucleus. Together with colleagues (Dr Carla Moran, Dr Nadia Schoenmakers, Dr Mark Gurnell) at the Institute of Metabolic Science in Cambridge, he outlined how they study patients with rare genetic abnormalities affecting the action of thyroid hormone at any of these levels. Professor Chatterjee explained how it is hoped that knowledge gained from studying these rare disorders will better inform the management of common thyroid conditions such as hormone replacement in hypothyroidism or lead to the development of new agents (e.g. cholesterol-lowering drugs) which target thyroid-regulated processes.

**BTF PROJECTS UPDATE**

**Iodine project update**

The UK Iodine Group (formerly UK Iodine Status Strategy Group), of which BTF is a member, is continuing its work to raise awareness of the importance of iodine for those with a normal functioning thyroid gland. For people with a properly functioning thyroid, iodine is essential as it is required for the production of thyroxine. It is particularly important in women who are pregnant as it is needed to ensure the development of a baby’s brain during pregnancy and early life. People who are taking replacement thyroxine (levothyroxine) however do not have a functioning thyroid to absorb iodine and therefore iodine is not required. Adding an iodine supplement in people being treated for hyperthyroidism is unnecessary and can worsen the condition.

The UK Iodine Group has produced a mission statement which sets out our vision:

To ensure optimal iodine nutrition in all sectors of the UK population in order to avoid the adverse effects of iodine deficiency;

and our mission:

To promote awareness of the importance of iodine in the diet and to make evidence-based recommendations to eradicate iodine deficiency in the UK.

The Standing Advisory Committee on Nutrition (SACN), an advisory committee to the Chief Medical Officer of England and the Department of Health (DoH) has recently issued a paper on iodine status in the UK:


Although The UK Iodine Group has concerns regarding some aspects of this document we were pleased to note that DoH has issued a research call on iodine: http://www.nihr.ac.uk/proposals/Lists/NIHR%20Calls%20for%20Proposals/DispForm.aspx?ID=332

Professor Margaret Rayman and Dr Sarah Bath, members of the UK Iodine Group, are preparing an application for submission.

The iodine status of Europe (including UK) was the subject of a leader published in The European Thyroid Journal by John Lazarus: Lazarus JH. Iodine status in Europe 2014. Eur Thy J 2014.

Further publicity regarding iodine deficiency in UK was presented at the recent BES meeting in Liverpool (see page 4).

**Hypothyroidism care strategy project update**

Julia Priestley writes: We are delighted that Professor Scott Wilkes, Professor of General Practice and Primary Care at the University of Sunderland and Professor Simon Pearce, Consultant Endocrinologist and Clinical Lecturer in Endocrinology at Newcastle University have joined our project team. It is invaluable to have their professional input and guidance to help us communicate the key messages about hypothyroidism that we are working to promote.
Fundraising And Donations

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

If you are employed, please check with your employer to 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.

Lesley Antrobus took part in the Balfron 10K run again this year despite recent back surgery and raised a fantastic £335. Her daughter Becky was born with congenital hyperthyroidism so Lesley is keen to support the BTF’s work.

Jason Cook and a host of his comedy pals staged the second Hebburn Charity Gala. The event, at Hebburn RAOB Club on Friday, April 25, raised £1250 for the BTF. Jason, who wrote the TV comedy sitcom Hebburn, performed alongside fellow comic Steffen Peddie and South Shields singer Rosie Winter, as well as some surprise guests and familiar faces from the BBC2 sitcom and it was a roaring success.

We had three runners raising funds for us in the 2014 Virgin Money London Marathon:

- Sam Carpenter a thyroid cancer survivor who has been in remission for two years and wanted to do something to celebrate this and to raise money at the same time. She managed to raise nearly £500!

- Selim Auckburally who has had an under-active thyroid since the age of ten and wanted to run for a charity close to him and his mum’s heart. His run went well despite pulling both calf muscles! He has raised an incredible £1000 from sponsorship which includes a £250 donation from the firm he works for, Price Waterhouse Coopers.

- Ben Lam Hang ran in memory of his mum Kim who passed away from thyroid cancer last year. He has raised nearly £800 and managed to run in a tiger onesie!

- Cathryn Holman ran the Brighton Half Marathon and raised nearly £900 (including £182 from her place of work, Towers Watson through match funding). She decided to run for the BTF because she has received personal support since being diagnosed with Hypothyroidism and Hashimoto’s Disease in 2011. Cathryn said after the race: ‘I don’t have to put my life on hold because of this condition - I have been able to work with it and I can accomplish the goals I set myself.’

- Adele Hayes, age 11, raised an amazing £120 by raffling crochet gifts she hand made herself and selling them to her class. Adele has been knitting and crocheting since she was a young girl and decided to fundraise for the BTF as her sister has congenital hypothyroidism.

- Jennifer Spencer-Charles completed an Iron Man Triathlon over six weeks and raised £400! She was diagnosed with Hashimoto’s two years ago. She said ‘Many people, like myself have spent many years dealing with the symptoms that get progressively worse, when all it takes is a simple blood test.’ She swam 2.4 miles, ran 26.2 miles and cycled 112 miles from 12 April to 25 May (World Thyroid Day).

- Somer Turnbull took part in the 5k Garioch Run in March 2014 and raised almost £300 with her friend Erin Gauld. In 2012 Somer was diagnosed with an under-active thyroid so being able to relate to the BTF has made her want to help.

- Heather Brookes walked the West Highland Way in April and raised an amazing £900! For the past five years Heather has had Graves’ disease and suffered from an over-active thyroid. Heather walked with her family and the walk was a whopping 96 miles in total!

- Bella Smith and her brother Edward took part in the BUPA Great Manchester Run in May and raised over £100. Their mum was diagnosed with thyroid cancer in the summer and the whole family is dedicated to raising money and awareness of the disease.

- Kayley and Lucia Crankshaw took part in a ‘Superhero’ Run in May dressed as Batman and Robin to raise awareness of the BTF as they both have people close to them affected by thyroid issues. They raised nearly £300 between them.

- Lauren Brooks embarked on a 50 mile walk in June and raised over £200. Lauren suffers from a thyroid disorder and really wanted to raise money to support the BTF.

- Sara Mason raised £120 instead of gifts for Nathanlee and Elizabeth’s christening as a few members of her family have hypothyroidism including her son Jamie and nephew Max.

- Michelle Pegg ran in the Edinburgh Half Marathon in May and raised £75. She was supporting the BTF as she has many...
people close to her that are affected by thyroid disorders.

Sarah Pidsley completed a 20 mile bike ride in June for the BTF around Ellesmere Port and raised over £200.

Two runners, Dave McGrath and Lawrence Priddle ran the Southend Half Marathon in June. Dave raised nearly £500 and ran because his fiancée, big sister and mum all suffer from thyroid problems and have found the BTF to be a great source of support. Lawrence was running as his girlfriend Megan suffers from Graves’ disease. He raised a fantastic £403.

Joanne Lloyd took on the National Three Peaks Challenge for the BTF (as we went to press) and is aiming to raise £500.

We have six runners taking part in the annual British 10k Run in London on 14 July. Five are members of the BTF London Local Group: Denise Sims (the new BTF local coordinator for London), Cathryn Holman, Caroline Crowley, Julie Lofting and Karen George.

www.justgiving.com/LondonTeddyRunners

The sixth runner is Katja Gomer who had such a fantastic time at last year’s run she has decided to take part again.

A big thank you to all our fundraisers!

Future fundraisers

Carly Mathews and Alix Hampton are taking part in a ‘Moonlight Colourthon’ in July.

www.justgiving.com/Carly-Mathews

Sandra Banfield is taking part in a 13 mile walk/run/cycle event with her local running group ‘the Dolly Mixtures’ in August. She suffers from Graves’ disease, and she has had a frightening and painful journey back to good health.

Kevin Savage is running the Great North Run in September. His nephew Jamie suffers from a thyroid condition. He said ‘for those who know me well, you will know I can barely run up the stairs! So if you could even sponsor me 50p I would be very grateful’.

www.justgiving.com/Kevin-Savage1

Syz (Simon) Goss will be taking part in ‘The Spartan Race Trifecta’ in September. His daughter Tiffani was born without a thyroid gland.

www.justgiving.com/SyzGoss

Emily Heseltine will be taking part in the Bristol Half Marathon in September. She has suffered from an over-active thyroid for four years and it has been a long and painful process to correct it.

www.justgiving.com/Emily-Heseltine2014

Steve Robb, a veteran fundraiser for the BTF, is now undertaking an incredible three marathons and a half marathon for us in 2014. His daughter Eilidh was born with congenital hypothyroidism and Steve is determined to raise as much funds as he can for the BTF. He ran the Aloa Half Marathon in March (with his friend David Wilkie), the Manchester Marathon in April and the Strathearn Marathon in June. He plans to also run the Highland Perthshire Marathon in September 2014.

www.justgiving.com/steverobb

Theo Hiden who suffers from hypothyroidism and his friend Maisie Wood are doing the Mini Great North Run in September in aid of BTF. They are just three years old and will be running 1.5km!

www.justgiving.com/TheoHiden

Naomi Leacock and Jo McGurk are going to take part in a ‘Total Warrior’ Event in August 2014. One of their colleagues at work has been battling thyroid cancer for some years now and is still undergoing treatment for this. They said ‘We are fundraising for the BTF because we hope that we can make a difference and be able to give others the opportunity that we have to live their lives as we do’.

www.justgiving.com/Naomi-Leacock09

Gail Leith is celebrating her 50th birthday in August and has organised a party. She has asked her guests to donate to the BTF as she was diagnosed with thyroid cancer 10 years ago.

www.justgiving.com/gail-leith

Catherine Preedy is taking part in the Cardiff Half Marathon in October after being diagnosed with hypothyroidism three years ago.

www.justgiving.com/catherinepreedy

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.

The Spectrum Club Dudley members held a raffle and raised £300.

IRRV East Midlands Association President’s charity for 2013/14 held a variety of fundraising events and raised £1,408.68.

Carole Ingham a former BTF local coordinator, raised £400 for the BTF in memory of her husband Ian.

Brenda Conroy raised £255 in memory of her husband David Conroy.

David Sharkey donated $1000 after a friend of his, who has recently been diagnosed with a thyroid condition, moved to the UK. The amount was match-funded by Bank of America who he works for.

This year Poulton le Fylde Golf Club has again nominated the BTF as its Captain’s Charity for the 2014-2015 season. The newly appointed Captain, Jeremy Stephenson (Jem), chose the charity in memory of Nicola Worrall who sadly passed away in December 2013 aged just 32.

Nicola had been a great supporter of the BTF following the sad death of her mother, Lynda Lawton, when she was young from a thyroid related illness. Only late last year Nicola took part in the Blackpool Autumn Breaker 10k run to raise funds for the BTF.

Nicolawas also instrumental in helping raise over £4,700 when Poulton le Fylde Golf Club last nominated the BTF in the 2009-2010 season by completing a Manchester to Blackpool bike ride as well as other fundraising activities at the golf club.

This year Jem has numerous activities planned including auctions and raffles, regular race nights, a charity cricket match, a charity golf day (where he will look to create some kind of speed golf record) and other events during his tenure as Captain.

Donations in memory of Nicola are gratefully accepted at BTF and at www.justgiving.com/btf/donate

Nicola with her son Luke

Blackpool bike ride as well as other fundraising activities at the golf club.
Keisha Hunn explains how she struggled with the diagnosis and treatment of her over-active thyroid as a young child but after successful treatment is feeling confident about life again.

I was diagnosed with an over-active thyroid at the age of seven. I am only 17 now so I have suffered with this condition for the past 10 years of my life. In some ways it has been quite lonely, which is why I was so happy to see the ‘My Story’ page on the BTF website!

Thyroid issues in children are obviously very rare, which is why it had never been picked up on before. As a child I had Attention Deficit Hyperactivity Disorder (ADHD), so I was under a specialist for this, but my nan noticed that my eyes always bulged and I had a large goitre. She immediately pointed this out to my mum, who then spoke to my ADHD doctor about this. Because of my age, my doctor said she bet her year’s wages I would have the blood test and it would come back negative because it’s just so rare in children. I had the blood test, and to her surprise, it came back positive.

As a child, I didn’t really understand what this meant. No one had ever spoken to me about thyroid issues before, I didn’t even know what a thyroid was so it didn’t really affect me that much. The only thing that did bother me was the blood tests that I had to do every 3-6 months and the constant discomfort when wearing shirts with top buttons, as previously they used to be really tight on my neck where it bulged out so much! I find out this summer how successful the treatment actually was and if I’m going to need any further treatment.

Keisha added some reassuring words for others in a similar situation: ‘Believe me, it all gets so much better, although you may not feel particularly great about it now, you’ll be fine in the end!’

You can read other inspiring stories on the BTF website www.btf-thyroid.org under ‘Your Thyroid/Share Your Story’.

Children’s Corner

If you are a young person with a thyroid disorder we would love to hear from you about your experiences of managing your condition and coping with any problems you may have had along the way. We know how invaluable it can be to read about other people’s experiences so please let us know how you feel about your thyroid, by sending in poems, stories or artwork – however you like to express yourself!

If you would like information or have a question you can write in to BTF, Second Floor, 3 Devonshire Place, Harrogate HG1 4AA or email children@btf-thyroid.org. We will ask our children’s medical adviser, Dr Tim, to reply and may publish the letter in the Children’s Corner. If you are under 18, don’t forget to ask your parents to state in your letter or email that we can publish what you send us.

The main types of thyroid problems in children:

An underactive thyroid gland in babies (congenital hypothyroidism)

Sometimes people are born without a thyroid gland or with a gland that is too small. When this happens they don’t get enough thyroid hormone because their thyroid gland ‘factory’ is not properly built. These babies are usually picked up by a blood test spot a few days after birth and are treated with thyroid hormone replacement (levothyroxine) which is the same as the natural thyroid hormone. Thyroid replacement hormone works very well so an underactive thyroid shouldn’t stop children leading a normal life.

An underactive thyroid gland due to antibodies (Hashimoto’s disease)

In this condition antibodies attack the thyroid gland by mistake and damage it. Sometimes it is obvious that something is wrong because the thyroid gets big but sometimes it happens without the person knowing anything about it until they become underactive. In this case they may have problems such as tiredness, feeling cold and slow growth. Thankfully this problem is quite easy to treat as well by putting back the thyroid hormone – either as tablets or in liquid form.

An overactive thyroid (Graves’ disease)

Antibodies can also make the thyroid go overactive because they switch the gland on and tell it to make extra thyroid hormone continuously instead of just when it is needed. This can make people feel poorly and stop them from concentrating and sleeping properly. An overactive gland can be more difficult to treat than an underactive one. Some people will be given an anti-thyroid medicine to take by itself (usually carbimazole) which reduces the amount of thyroid hormone made by the thyroid gland. The amount can then be adjusted until the thyroid hormone levels are normal. Other people are given a bigger dose which stops the gland from working completely. The body’s need for thyroid hormone can then be met by levothyroxine to replace the missing hormone. This type of treatment is called ‘block and replace’.
The reports stated that scientists have found a genetic variant that may increase the risk of having a lower IQ. Dr Taylor and his colleagues have identified that children under seven with a common gene variant together with low levels of thyroid hormone were four times more likely to have an IQ below 85. The researchers took a large population (3000) of normal children about whom they had detailed information on their early life and home environment and looked at whether children with lower thyroid hormone levels and this genetic variant were more likely to have a lower IQ. The study found that in a typical class of 30 children, four will have the variant and one of these will also have lower thyroid hormone levels and have a higher chance of a lower IQ. The other three children with the variant, but thyroid hormone levels not so low will not be affected. This highlights that both the genetic variant and lower thyroid hormone levels need to be present to have the increased risk of a lower IQ.

Dr Taylor said ‘If further studies confirm our findings, then potentially there may be a benefit in carrying out a genetic test for this gene variant along with the standard neonatal thyroid screening in order to identify those children most at risk of developing low IQ. We could then potentially in the future also carry out genetic testing on children with borderline blood tests too’.

RESEARCH IN THE MEDIA

In March, the national press (including the Sunday Times and Sunday Telegraph, 23 March 2014) reported on findings presented by Dr Peter Taylor (lead researcher at the University of Cardiff’s School of Medicine) at the Society for Endocrinology’s BES conference in Liverpool (see page 4).

The reports stated that scientists have found a genetic variant that may increase the risk of having a lower IQ.

Dr Taylor and his colleagues have identified that children under seven with a common gene variant together with low levels of thyroid hormone were four times more likely to have an IQ below 85. The researchers took a large population (3000) of normal children about whom they had detailed information on their early life and home environment and looked at whether children with lower thyroid hormone levels and this genetic variant were more likely to have a lower IQ. The study found that in a typical class of 30 children, four will have the variant and one of these will also have lower thyroid hormone levels and have a higher chance of a lower IQ. The other three children with the variant, but thyroid hormone levels not so low will not be affected. This highlights that both the genetic variant and lower thyroid hormone levels need to be present to have the increased risk of a lower IQ.

Dr Taylor said ‘If further studies confirm our findings, then potentially there may be a benefit in carrying out a genetic test for this gene variant along with the standard neonatal thyroid screening in order to identify those children most at risk of developing low IQ. We could then potentially in the future also carry out genetic testing on children with borderline blood tests too’.

MEDICINES UPDATE

Latest news about levothyroxine and Eltroxin tablets from Amdipharm Mercury (AMCo)

AMCo have produced literature for patients to help clear up any confusion about which products are available, and to provide a full comparison of products marketed by AMCo - branded Eltroxin and generic levothyroxine. Both the generic and branded AMCo products are available as 25, 50 and 100 microgram (mcg) strength tablets. In the UK all medicinal products (such as levothyroxine and Eltroxin) are identified by their Product Licence (PL) number which is printed on the immediate packaging (carton, label and foil). All branded (Eltroxin) products manufactured under a particular PL number are also licensed under the generic name (levothyroxine). These products are identical in every way. Thus the 25mcg, 50mcg and 100mcg tablets, whether branded (Eltroxin) products or generic (levothyroxine), with the same PL number, are identical, except for the packaging.

The 50mcg and 100mcg tablets are each currently available under two different PL numbers. The 100mcg tablets marketed under the two different PL numbers are identical. For the 50mcg strength tablets, there is a very minor difference between products manufactured under different PL numbers in the amount of powdered acacia (an inactive binder) that the tablets contain. Apart from this, the products are exactly the same. AMCo has made changes to its licences in order to ensure that the amount of powdered acacia manufactured in future is the same. Therefore, there will be no difference in the tablet compositions for all levothyroxine and Eltroxin 50mcg tablets manufactured in future.

Manufacture of the 50mcg tablets under PL 16201/0001 and 100mcg tablets PL 16201/0002 will cease from around July 2014, effectively bringing into line the PL number by which both branded (Eltroxin) and generic (levothyroxine) AMCo products are identified. Full information is available on the BTF website: www.btf-thyroid.org
Good thyroid function is an important factor in becoming pregnant and carrying a healthy baby to term. There are many reasons for difficulties in conceiving in couples - a poorly functioning thyroid being an often overlooked factor particularly in female subfertility.

According to Professor Simon Pearce, Consultant Endocrinologist at the Royal Victoria Infirmary in Newcastle upon Tyne, ‘Undetected thyroid problems can cause significant problems with fertility but are generally straightforward to correct once identified.’

The symptoms of a poorly functioning thyroid can often be subtle so it is important for women to see their GP if they have been trying to conceive for longer than a year to check their thyroid is functioning correctly before starting other medical procedures. This is particularly important if they have a history of thyroid disorders in their family as many are inherited.

A normally functioning thyroid gland is essential to ovulation, implantation and maintenance of a healthy pregnancy. Thyroid hormones, previously thought not to affect male fertility, are also now being recognised as playing an important role, for example in sperm production.

The most common type of thyroid disorder in child-bearing women is hypothyroidism. Low levels of thyroid hormone can interfere with the release of an egg from the ovaries (ovulation), which impairs fertility. In addition, some of the underlying causes of hypothyroidism, for instance Hashimoto’s thyroiditis, appear to also impair fertility.

Treating hypothyroidism in women is an important part of any effort to correct infertility: women who have hypothyroidism and hope to become pregnant, need to work with their doctor to make sure their hypothyroidism is under tight control. Women who have hypothyroidism and become pregnant, need to tell their doctor as soon as possible. Close monitoring of thyroid hormone levels during pregnancy can help normal fetal development and reduce the risk of miscarriage.

Most women already on levothyroxine tablets and who become pregnant will need to increase their dose during pregnancy. Often, this dose increase will be needed as soon as the women knows she is pregnant.

Women who have an overactive thyroid should contact their endocrinologist if they are pregnant or are planning to become pregnant because they may need to change their medication and have more frequent blood tests throughout the pregnancy. There is a small risk of birth defects with all antithyroid drugs during pregnancy, but such treatment is safer to both mother and baby than uncontrolled thyroid overactivity during pregnancy. You should discuss these risks with your endocrinologist before embarking on pregnancy.

It is safe for pregnant women to take tablets for both an overactive and underactive thyroid during pregnancy. Indeed, adequate thyroid hormones are essential for a baby’s neurological development whilst in the womb.

The overriding message from the professionals is that the earlier thyroid problems are acted on in pregnancy the better the outcome for the unborn child.

International Thyroid Awareness Week 25 - 31 May 2014 highlighted infertility as one of the ‘five reasons to be aware of thyroid disease’ (see page 2).

MEET THE PRESIDENT OF THE BRITISH THYROID ASSOCIATION

Dr Mark Vanderpump

Dr Mark Vanderpump MB ChB MD FRCP was elected President of the British Thyroid Association (BTA) in April. The BTA is a non-profit making Learned Society of professional clinical specialist doctors and scientists in the UK who manage patients with thyroid disease and/or are researching into the thyroid and its diseases in humans. The BTA works closely with the BTF.

Dr Vanderpump is Consultant Physician and Honorary Senior Lecturer in Diabetes and Endocrinology at the Royal Free Hampstead NHS Trust in London. Prior to this he was a consultant endocrinologist at the North Middlesex Hospital NHS Trust. His training in general medicine and endocrinology was completed at posts in the West Midlands, North East England and North Staffordshire.

His main area of expertise is thyroid disease but his clinical practice includes all aspects of diabetes and endocrinology. He has published on various aspects of thyroid disease and served on the Executive Committee of the BTA between 2002 and 2008.

What do you hope to achieve during your term of office as BTA President?

It is a great honour and privilege to be elected as BTA President. I am enormously grateful to my predecessor Professor Graham Williams for leaving the BTA in such a strong position and for his tremendous contribution in developing the BTA during his term. When I was the BTA Secretary in 2004 the BTA Executive Committee held an ‘away day’ to analyse the strengths and weaknesses of the BTA with the aim of formulating a long-term strategy. The main strengths agreed and that have remained are the high quality of the membership, the increasingly popular scientific meetings and the continuing development of our liaison with the BTF. Thyroid disease and pregnancy is an increasingly important area where we hope to provide clear treatment guidance. The emerging issue of iodine deficiency in young women in the UK will need to be recognised and addressed by the public health authorities. I hope to build on those acknowledged strengths promoting clinical and basic thyroidology and the needs of patients with thyroid disorders.

What is your view of the collaboration with the BTF, and how can we help each other and make a difference?

I have been a Trustee of the BTF for two years and have been hugely impressed with all their work and support to patients as well as the BTA, much of which is behind the scenes. The BTF has played a vital role in the UK Iodine Group (formerly the UK Iodine Status Strategy Group (UKISS)) and recently in promoting the care of children with thyroid disorders. The BTF recognises that engagement and education of our primary care colleagues is crucial in supporting patients with thyroid disorders. The continuing controversies regarding the assessment and management of primary
hypothyroidism remains a difficult area of our clinical practice in which we are often criticised for practising evidence-based medicine. I am very supportive of the BTF in the recent initiative to improve the care of patients with hypothyroidism.

**What is your vision of how thyroid patients should be managed and how would you like to see this develop in the coming decade?**

I am increasingly being asked about the feasibility of telephone and virtual clinics to manage patients with thyroid disorders which appear to be increasingly popular amongst commissioners of health care. Many patients with thyroid disorders are increasingly being denied access to specialist input so it is crucial that the BTA provides support to primary care teams who will often be providing care for the majority of patients. The BTA will be required to lead on setting high quality standards for management of patients in the future NHS and providing patients with information about their thyroid disorder.

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**BTF RESEARCH AWARD WINNERS**

**Dr Vicky Smith**

MRC Research Fellow, School of Clinical and Experimental Medicine, University of Birmingham who was awarded the BTF Research Grant in 2012; has sent in her final report:

**Characterisation of thyroid structure and function in the PBF knockout mouse**

PBF is a protein that is present in the thyroid and is upregulated in both benign and malignant thyroid disease. We have shown that PBF can downregulate two proteins that are important for normal thyroid function, namely NIS and MCT8. NIS takes up iodide from the blood into the thyroid and is therefore important for thyroid hormone synthesis, and MCT8 secretes thyroid hormone from the thyroid into the blood. NIS is also important for radiiodine uptake and hence increased PBF protein can impact on critical treatment of thyroid cancers and their metastases.

Multinodular goitres contain increased levels of PBF, and mice that have high levels of PBF in the thyroid develop large goitres. Thyroid cancers with higher levels of PBF are more likely to recur and become metastatic, and are associated with a reduced survival rate. However, the way in which PBF affects thyroid growth and cancer development is not fully understood.

These studies indicate that PBF is an important regulator of the thyroid and to understand more about how it does this, we aim to characterise a mouse which does not have the PBF protein, a PBF knockout mouse. Our main objectives are to analyse the effect of not having PBF on the growth and development of the thyroid and on how the thyroid functions.

Our initial studies were very promising, with the successful production of chimere mice showing a high level of contribution from the cells containing the PBF deletion. However, genetic screening of subsequent generations of mice revealed that cells with PBF deletion were not being passed from generation to generation. We therefore discovered that PBF is likely to be important in the process of reproduction, making it difficult to obtain a model in which we could study the thyroid.

To overcome this we therefore switched to creating a mouse in which PBF is only deleted in thyroid cells. We have done this by manipulating cells grown in vitro (in a dish in the laboratory) so that they will produce the PBF protein normally until we trigger the deletion specifically in the thyroid. It was possible that the deletion of PBF in non-thyroid cells may have also altered thyroid growth and function (perhaps through altered hormone secretion). This new model, which is currently under evaluation, will therefore now show us more specifically what effect losing PBF has on the thyroid gland.

Alongside this work, we have continued to intensively investigate the mechanism by which PBF inhibits radiiodine uptake via the NIS transporter. Importantly, we have recently shown that we can use a drug to restore iodide uptake following repression of the NIS protein by PBF in thyroid cells. Our future research will involve the use of both the thyroid-specific knockout mouse and drug treatment in models of thyroid cancer and goitre. This will enable us to understand more about how PBF contributes to thyroid disease and assess PBF as a therapeutic target to improve radiiodine treatment of thyroid cancer.

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**Peripheral blood microRNA markers in patients with papillary thyroid cancer:**

About 2,500 people are diagnosed with thyroid cancer in the UK every year. The majority survive for many years, but have to have checks regularly as the cancer can return even 30 years after the original diagnosis. Doctors have a very useful blood test available called a ‘thyroglobulin test’, which can signal early if the thyroid cancer is beginning to come back. So a negative thyroglobulin test is very reassuring for both patient and doctor and such patients can be followed up less frequently. Unfortunately, the thyroglobulin blood test in about a third of people with thyroid cancer is made useless by the presence of antibodies in the bloodstream. Since the thyroglobulin blood test was invented in the early 1980s no other better diagnostic test has been forthcoming. Recently interest has focused on detecting chemicals in the bloodstream called ‘microRNAs’. They are thought to be released by circulating cancer cells and can act as markers of cancer.

With the generous support of a BTF grant, we embarked on a project to explore the science and recently found that ‘microRNAs’ are present in the bloodstream of people with thyroid cancer.

**Dr Petros Perros, Consultant Endocrinologist at the Royal Victoria Infirmary, Newcastle and winner of the BTF Research Grant in 2013 has sent a six month report about his study so far:**

Peripheral blood microRNA markers in patients with papillary thyroid cancer:

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**Continued on page 12**
use of microRNAs in thyroid cancer. We used blood samples from patients who we were confident had no cancer and patients who we knew for certain still had cancerous cells in their body. We tested them for differences in microRNAs in the circulation. The preliminary analysis has shown that there were 18 microRNAs that were different between the groups. This could mean that some of these markers may be used to identify patients with thyroid cancer. These results need to be verified, but we are very encouraged at this stage and we plan to do some more analyses on the data.

**BTF AWARDS**

*Each year we invite applications for two awards: the British Thyroid Foundation Research Award and the Evelyn Ashley Smith Award for nurses.*

**BTF Research Award**

The deadline for this year’s award of £20,000 is 31 August 2014. We invite applications for research that is specifically directed to the study of thyroid disorders or investigations into the basic understanding of thyroid function.

**Evelyn Ashley Smith Award for nurses**

BTF is offering two awards for nurses, endocrine nurses, midwives and healthcare professionals with an interest in thyroid disorders. The award of up to £500 is to help cover conference/training expenses, including registration fees and/or travel costs. The award of up to £1000 is to help support a specific project lasting one year; or support an on-going project; or reward a piece of work already completed, but not yet published. You may apply for both the £500 Nurse Award and the £1000 Nurse Award provided that each award is completed on separate application forms. The closing date for receipt of applications is 1 July each year.

Please see the BTF website www.btf-thyroid.org for more details and an application form.

**RESEARCH FROM AROUND THE WORLD**

**Treatment decisions in patients with subclinical hypothyroidism**

Patients with a slightly increased thyroid stimulating hormone (TSH) level but normal free T4 levels are diagnosed as having subclinical hypothyroidism. Treatment of these patients with thyroid hormone is controversial as over-treatment can cause problems including abnormal heart rhythms and bone loss leading to osteoporosis. (The British Thyroid Association recommends treatment if TSH concentration is higher than 10 mU/l. Treatment can be initiated at lower levels depending on clinical need for instance if the patient is considering pregnancy.)

A recent study of the UK-wide database of patients receiving thyroid hormone replacement therapy has been carried out to assess the level of over-treatment. The study evaluated 52,000 patients receiving an initial prescription for thyroid hormone replacement therapy. It was found that from 2001 to 2009 the average TSH for which a new patient received thyroid hormone therapy fell from 8.7mU/L tp 7.9mU/L with people 30% more likely to be prescribed levothyroxine at lower levels in 2009 than 2001. As a result approximately 83% of the patients started on thyroid hormone replacement therapy had a normal free T4 prior to starting therapy. After 6-12 months of treatment, 6.3% of patients were found to be hyperthyroid from their medication. After 54-60 months of treatment, 10.2% were over-replaced and biochemically hyperthyroid.

Taken together this suggests that more patients with marginal indicators of hypothyroidism are being started on thyroid hormone replacement and that these patients are at significant risk of over-treatment. The authors of the study cautioned that GPs need to be aware of this trend before starting patients on long term thyroid hormone replacement and once therapy has begun regular monitoring appears to be needed to prevent overtreatment.

**Possible link between maternal thyroid dysfunction and offspring autism and ADHD**

Researchers from Aalborg University and Aalborg University Hospital in Denmark have identified a potential correlation between maternal thyroid disease that is first diagnosed and treated in mothers after the birth of a child and the risk of autism or ADHD in their offspring.

Researchers reported that based on a total population sample of 800,000 children over 30,000 were born to mothers with some kind of thyroid dysfunction. Where maternal hypothyroidism was diagnosed there was a slightly increased risk of their offspring being diagnosed with ASD, whereas a diagnosis of maternal hyperthyroidism had a slightly increased risk of offspring being diagnosed with ADHD.

Taken from www.autismdailynewscast.com

Source: Anderson, S et.al. Attention deficit hyperactivity disorder and autism spectrum disorder in children born to mothers with thyroid dysfunction: a Danish nationwide cohort study. BJOG. 2014 March 10

**Dr Perros, medical editor comments:** The results from this study are not easy to interpret. The findings suggest an association between maternal thyroid disturbance detected after childbirth and ADHD and ASD. This association is rather weak, though statistically significant. So, the first point to make is that even if these observations are correct, cause and effect cannot be assumed. Furthermore, as the authors point out there are other studies that do not confirm this trend and some that show an association in the opposite direction, ie ADHD being linked with...
Hyperthyroidism and cholesterol

NR asks: I wonder if you might be able to tell me if there is a link between hypothyroidism and high cholesterol?

I have been treated with levothyroxine for just under five years and for at least four of those years until recently was on a dose of 175mcg per day. Following a routine blood test, my doctor reduced this to 125mcg. Following a further blood test six weeks later, he advised me that I should drop the dose further to 100mcg but also advised me that he was ‘very surprised’ to see I had cholesterol levels of 7.2.

I asked if there was a link between the two and he thought not but I wondered if you might have any further information.

Our medical advisor replies: Yes, untreated hypothyroidism is a well-recognised cause of high cholesterol. Once you have been treated though, it generally goes back to normal if the hypothyroidism was the cause. If you have borderline hypothyroidism (subclinical), then the average drop in cholesterol is 0.2 mmol/l following treatment with levothyroxine, so for most people there isn’t a massive difference.

Many women have high total cholesterol and high good cholesterol, which is called HDL [high-density lipoprotein]. It’s very important not to get treated for high cholesterol if it’s attributable to high HDL as the treatment probably worsens your risk of heart problems not the other way round. There are very few reasons to treat a 35 year old woman for high cholesterol and I suggest you should be reticent to accept any medication until a full profile has been done (i.e. the HDL has been measured).

Thyroid nodules

NS asks: Doing some research on the web regarding my wife’s condition, I came across your website. For nearly 40 years she has been suffering with non-cancerous thyroid nodules. About 30 years ago she was due to have an operation to remove her thyroid gland. At the last visit with the consultant, she was told there would not be a need for an operation because the nodules had disappeared. Now in 2014 after her most recent visit to the hospital she was once again told she would need to have her thyroid gland removed and would be on medication the rest of her life.

On the web, I saw a mention about laser ablation thus removing only the nodules, which in my opinion would definitely be preferable. Although this has been pioneered in the US (in 2006) I am struggling to find any mention of it in the UK.

I will be very much obliged if your organisation has any knowledge of practitioners who carry out this procedure in the UK.

Our medical advisor replies: Thyroid nodules are common and can affect up to 50% of the population, mainly older women. The risk of cancer is very low and most nodules can be managed conservatively. If the nodule causes problems particularly if it is growing, causing symptoms or is a cosmetic concern AND once cancer has been excluded then surgical removal has been the mainstay of treatment for decades. In the last decade newer therapies have been suggested for managing thyroid nodules such as alcohol injection (mainly if the nodule is cystic – that is, contains mainly fluid and recurrent after aspiration) and radiofrequency ablation, laser treatment, microwave or high frequency ultrasound treatment for solid non-cancerous nodules. All these procedures are in their infancy and a number of centres worldwide are still gaining experience in their use. In Europe, laser ablation of solid thyroid nodules has mostly been used in Denmark and Italy but not in the UK, as far as I am aware. These European groups are still publishing their experiences as part of trials. In inexperienced hands, these procedures are not without risks – damage to the vocal cord, laryngeal nerve (nervus to the voice box) and severe transient pain has been reported. These issues are likely to be more frequent in operators who are still gaining experience rather than fully trained personnel.

Unnecessary surgery?

CB asks: I am British and currently living in Johannesburg, South Africa. On a recent routine examination a nurse could see a swelling in my neck, which led to an ultrasound examination. The report says it is probably a colloid nodule. I have seen a maternal hypothyroidism (not hyperthyroidism). This is an example of how large databases can be used to look at trends and potential links, but usually little more as the biases are great. They can be however the starting point for designing more robust studies that may potentially be able to answer important research questions.

Link between thyroid disease and ethnicity

A new study by researchers in Australia appears to have found a link between race and a person’s risk of developing autoimmune thyroid conditions such as Graves’ disease or Hashimoto’s thyroiditis. African Americans and Asians are much more likely to develop Graves’ disease than whites according to the study published in the Journal of the American Medical Association.

Conversely whites have an increased risk of Hashimoto’s thyroiditis. The findings are based on a study led by Dr. Don McLeod of the QIMR Berghofer Medical Research Institute in which the medical records from all United States active duty military personnel aged 20 to 54 from 1997 to 2011 was analysed.

‘We don’t yet know whether the differences seen are due to genetics, environmental exposures or a combination of both. But if these differences are due to racial variations in immune system pathways, in the future we could use this information to design new treatments or prevention for autoimmune disease.’ said McLeod.

The researchers now need to confirm that these patterns are seen in the wider population and are not specific to the US military.

‘Finding the root causes of thyroid autoimmunity has the potential to lead to prevention of thyroid disorders, and may also lead to crucial insights into other autoimmune diseases’

Taken from Asian Scientist www.asianscientist.com (April 28 2014) Sources: Donald McLeod, endocrinologist and researcher, QIMR Berghofer Medical Research Institute, Queensland, Australia; M.D., director, clinical endocrinology, Beth Israel Deaconess Medical Center, Boston; April 16 2014, Journal of the American Medical Association.
Continued from page 13

‘specialist surgeon’ who without even blinking wants to remove my right thyroid gland.

I am concerned that since most people have private health insurance here I am possibly having unnecessary surgery.

I have normal TFT results and don’t smoke. The blood test also showed I was anaemic.

Our medical advisor replies: Unfortunately, we are not able to formally advise as you live outside the UK. However it would be reasonable to state that in the UK it would be anticipated that a nodule would be subject to biopsy and the cells formally reviewed by a cytopathologist before a recommendation for surgery was made. Indications for surgery would include an abnormal biopsy result and/or a nodule that was increasing significantly in size and causing obstructive symptoms.

Second opinion

SH asks: I am hoping you can advise me, as I appear to have run out of options. I was diagnosed with Graves’ two years ago and have been on varying amounts of Propylthiouracil ever since. After an initial spike my levels have gradually dropped until a few months ago they were on the low side of normal. At that time I felt as though they were very much too low but continued on 50mg. My last appointment was a couple of weeks ago and I was convinced that I would be able to cease the drug, as I had no symptoms and felt very well, other than still carrying the 3½ stone that I had put on during treatment.

Rather than telling me I could cease the medication, I was told that my levels had increased and I would need to increase my tablets and decide on whether I would opt for the radioactive treatment or an operation.

I completely disagree with the test results. I feel fine and am very reluctant to increase the medication, let alone opt for more radical treatment.

Is there any likelihood that my ‘normal’ levels are above what my specialist considers to be acceptable? Could I just stop the medication altogether and see what happens? I feel I have nowhere to turn, I really do feel well and completely disagree with my consultant.

Our medical advisor replies: Thank you for contacting BTF. It is difficult to comment on this without knowing your blood test results, but a consultant would only be recommending this course of treatment if the blood tests were showing a recurrence of the thyrotoxicosis. It is not unusual for people who have been very thyrotoxic to feel well with milder levels of thyrotoxicosis.

We would therefore strongly advise you not to stop your medication without further medical advice as this could result in more severe thyrotoxicosis, which could be harmful in the long term. If you were not happy with the advice from your consultant we would advise you to ask for another appointment with the consultant so that you can raise your concerns. If you don’t feel able to do this, then you have the option of asking your GP to refer you for a second opinion.

Crumbling tablets

From former BTF Trustee Peter Foley

Over a period of the last two years I have noticed that the tablets in the Actavis packs have a tendency to crack and/or disintegrate when pushed from the blister. This makes them very difficult to use successfully and can cause additional difficulties for patients with eyesight impairments.

I contacted the company during summer 2013 and their reply was that they were aware of the problem with tablet quality and were doing their utmost to resolve it. The packs did in fact improve significantly but my last prescription of December has once again had a few split tablets.

Actavis are in smaller sheets of fourteen tablets with a rather tighter fitting blister than other manufacturers’ products and need more pressure to gain access to the tablet and therefore the extra pressure exerted may contribute to the breaking of the tablet.

If you have experienced similar problems we would like to hear from you. Email e.clegg@btf-thyroid.org

Local Groups

Please check the BTF website 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.

Belfast

NEXT MEETING: The group meets every first Thursday of every second month at 5pm. Check the BTF website for details.

LOCATION: Merchant Hotel, Belfast (High Street entrance).

CONTACT: Ursula Tel: 07720 659849 email: ursulajordan06@aol.com for further information.

Birmingham

NEXT MEETING: TBC. Check the BTF website for details.

LOCATION: Yardley Baptist Church, Rowlands Road, Yardley, Birmingham, B26 1AT. There is free parking available.

DONATION: £2 voluntary donation for venue costs and refreshments.

CONTACT: Janet Tel: 0121 628 7435 or email: janetdmp@googlemail.com

Cambridge

NEXT MEETING: Saturday 12 July 2014 from 10am -1pm

LOCATION: Friends’ Meeting House, Jesus Lane, Cambridge CB5 8BA.

PROGRAMME: To include a talk by Miss Rachna Murthy Consultant Ophthalmologist and Oculoplastic Surgeon at Ipswich Hospital and Addenbrooke’s Hospital and Dr Paul Meyer Consultant Medical Ophthalmologist at Addenbrookes Hospital.

DONATION: Suggested minimum donation: £3.
**Edinburgh**

**NEXT MEETING:** 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.

This meeting is a ‘drop-in session’ and anyone is welcome between 7.15pm and 8.30pm to discuss their particular thyroid condition and to get advice and support. Check the BTF website for further details.

**CONTACT:** Margaret Tel: 0131 664 7223 or email: M2mcgregor@aol.com

**Leeds (Wharfedale)**

**NEXT MEETING:** Details available soon - check the BTF website for details.

**LOCATION:** TBC.

**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**

Welcome to Denise our new Local Group Coordinator for London. She has taken over the role from Lorraine Williams.

(see page 2).

**NEXT MEETING:** Saturday 13 September 2014.

**Peterborough**

Welcome to Jennie, our new Local Group Coordinator! Please call her on 01733 391231 or email: jjo@coachingoutliers.co.uk if you would like to come along to a meeting.

FUTURE MEETING: Saturday 11 October 2014 at 10.30am. This will be a support group meeting.

**LOCATION:** The Pavilion, Open University, Milton Keynes, MK7 6AA.

Information events are held at 10.30am every three months. Check the BTF website for further details.

**DONATION:** £2 voluntary donation for room hire and expenses of running the group.

**CONTACT:** Wilma Tel: 01908 330290 or see: www.thyroidmk.co.uk or find us on Facebook.

**Notts/Derby**

**NEXT MEETING:** 1 September 2014 from 7 to 8.30pm.

The group will now meet every three months instead of monthly (excluding bank holidays). Check the BTF website for more details.

**LOCATION:** The Staff of Life public house, West End, Sutton-in-Ashfield, Notts, NG17 1FB.

**CONTACT:** Bridget on 01623 750330 after 6pm on weekdays and any time at weekends.

The BTF is very appreciative of our fantastic team: employees, volunteers, members, professionals, doctors and nurses who help the organisation to develop, as proved by our successful activities over the years.

**Patrons:**
- Clare Balding OBE
- Lord Jamie Borwick
- Jenny Pitman OBE
- Melissa Porter BA (Hons)
- Dr W Michael G Tunbridge MA MD FRCP
- Gay Search
- Josef Craig MBE

**Trustees:**
- Mr Richard D Bliss MA MB FRCS
- Angela Hammond (Vice Chair)
- Professor P Hindmarsh BSc MD FRCP FRCPCH
- Nikki Kieffer
- Bridget O’Connor
- Janet Prentice BSc (Hons)
- Professor Geoffrey E Rose BSc MS DSc MRCP FRCS FRCOphth
- Dr M Strachan MD FRCP (Edin)
- Mrs Judith Taylor BA (Hons) (Chair)

**Ex-Officio Members of the Trustees:**
- Dr M Vanderpump MB, ChB, MD, FRCP - President, British Thyroid Association

**Newsletter Disclaimer:**

The purpose of the BTF newsletter is to provide information to BTF members. Whilst every effort is made to provide correct information, it is impossible to take account of individual situations. It is therefore recommended that you check with a member of the relevant medical profession before embarking on any treatment other than that which has been prescribed for you by your doctor. We are happy to forward correspondence between members, but do not necessarily endorse the views expressed in letters forwarded.

Medical comments in the newsletter are provided by members of the medical profession and are based on the latest scientific evidence and their own individual experiences and expertise. Sometimes differing opinions on diagnosis, treatment and management of thyroid disorders may be reflected in the comments provided, as would be the case with other fields of medicine. The aim is always to give the best possible information and advice.

If you have any comments or queries regarding this publication or on any matter concerning the British Thyroid Foundation we would be pleased to hear from you.
**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.

- **Belfast** Ursula (U) 07720 659849
  - Belfast Ursula Jordan06@aol.com
- **Birmingham** Janet (PC,CS,RAl,PH) 0121 6287435
  - Birmingham Janetdmp@googlemail.com
- **Cambridge** Mary (O,RI,U) 01223 290263
  - Cambridge Marybutterflyecho@hotmail.com
- **Edinburgh** Margaret (PC) 0131 6647223

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<td>Edinburgh</td>
<td>Margaret</td>
<td>0131 6647223</td>
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<tr>
<th>City</th>
<th>Coordinator</th>
<th>Phone</th>
</tr>
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<tr>
<td>Leeds</td>
<td>Caroline</td>
<td>01132 866393</td>
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<tr>
<td>London</td>
<td>Denise</td>
<td>07984 145343</td>
</tr>
<tr>
<td>Milton Keynes</td>
<td>Wilma</td>
<td>01908 330290</td>
</tr>
<tr>
<td>Notts/Derby</td>
<td>Bridget</td>
<td>01623 750330</td>
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<tr>
<td>Peterborough</td>
<td>Jennie</td>
<td>01733 391231</td>
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**HPTH Helplines**
- South: 01342 316315
- North: 01623 750330

**Hypopara UK** Tel: 01943 873427

**AMEND**
- Email: janetdmp@googlemail.com
- Birmingham B34 7BY
- Tel: 0121 6287435

**OUR PARTNER ORGANISATIONS**

- **AMEND** Tel: 01892 516076 http://www.amend.org.uk
- **Hypopara UK** http://www.hpth.org.uk
- **HPTH Helplines** 01342 316315
- **Thyroid Cancer Support Group Wales** Tel: 08450 092737 http://www.thyroidsupportwales.co.uk
- **Butterfly Thyroid Cancer Trust** Tel: 01207 545469 http://www.butterfly.org.uk

**BRITISH THYROID FOUNDATION DETAILS**

**ALL ENQUIRIES TO:** The British Thyroid Foundation, 2nd floor, 3 Devonvon Place, Harrogate, North Yorkshire HG1 4AA.

Tel: 01423 709707 or 01423 709448 website: http://www.btf-thyroid.org.

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  - £35 Outside Europe
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