

Thyroid UK

Welcome to Thyroid UK E-News



Welcome to the April 2018 issue of Thyroid UK E-News!

Well, what weather we have had since our last issue. Lots of snow and lots of rain. Let's hope that the weather improves soon!

A lot has happened in the thyroid world since our last issue and so we will let you know in this issue what the updates are - the #T3Campaign; Scottish Parliament Petitions Report and the joint report of ITT, Thyroid UK and Thyroid Patient Advocacy.

We need your help in our #T3Campaign so do please support us - it will only take a short amount of time and it will really help people with thyroid disease who are really struggling at the moment.

I hope that you enjoy this issue. Have a good summer!

Best wishes,

Lyn Mynott and All at Thyroid UK



The Scottish Parliament
Pàrlamaid na h-Alba

Scottish Parliament Petitions Report

The Scottish Parliament Petitions Committee have produced a report on petition PE1463 - Effective thyroid and adrenal testing, diagnosis and treatment, 1st Report 2018 (Session 5).

The two main recommendations they have made are:

- The Committee considers it essential that professional bodies continue to work closely with patient support groups and individuals, such as the lead petitioner, so that greater awareness of guidance and patient experience is promoted. The Committee recommends that the Scottish Government ensures bodies within Healthcare Improvement Scotland also contribute to this work and that, in responding to this report, it provides an outline of how that contribution can be made.



About Us

Thyroid UK is a charitable company working primarily within the United Kingdom. Formed in 1998, we became a company limited by guarantee in 2007 and in 2008 we became a registered charity.

The provision of quality information for people with both diagnosed and undiagnosed thyroid disorders is the primary concern of Thyroid UK, and we work effectively in this field through dialogue with NHS departments, networking with other voluntary organisations, and providing services direct to patients

Our tag line is "Better Thyroid Health" and we are working towards this outcome for all patients of thyroid disease.



Charitable Bookings

- The Committee recommends that the Scottish Government brings the evidence received on the variation in thyroid testing in Scotland to the attention of the Scottish Clinical Biochemistry Managed Diagnostic Network. In doing so, the Committee suggests that consideration should be given to moving towards the development of a single, national protocol for testing, along with an accompanying process for issuing consistent advice to primary care practitioners for use when considering and interpreting diagnostic tests for suspected hypothyroidism.

You can find more information and the draft report here:

<http://www.thyroiduk.org/tuk/newspage.html#scottish>



**Update on our
#T3Campaign**

Thyroid UK has now registered with CHARITABLE BOOKINGS!

CHARITABLE BOOKINGS is an organisation that has produced a unique and free lifestyle app that raises funds for charities at no cost to you.

It has lots of great features including restaurant bookings, hotel bookings, recipes, restaurant deals and secret restaurant tips.

It's so easy to raise funds for Thyroid UK. Simply download the app and every time you want to book a restaurant or go away just check the app first to see if the restaurant or hotel is listed.

For every booking at over 8,500 restaurants across the UK, CHARITABLE BOOKINGS donates **£1 for every diner** and for every booking at over 250,000 hotels across the world, CHARITABLE BOOKINGS donates **£1 per guest for EVERY night's stay** (not up and running quite yet).

CHARITABLE BOOKINGS also has secret tips such as the best restaurant table numbers to ask for and deals at selected restaurants. You even get a chance to win money for us and prizes for yourself by playing their SWIPE game.

Get the app for free via Google Play or via the App Store, register and see what else is available and how to support Thyroid UK.

Alternatively, visit their website, register and start booking - <https://charitablebookings.com/>

Once you have registered, you will find a

Hunt, please let us know asap -

enquiries@thyroiduk.org

Members of the ITT group have met with Vince Cable who wants to do a debate in the House of Commons. If you have an MP who is sympathetic to the T3 problem, do let us know.

We now need you to help by writing to your MP sending the joint report and letting your MP know that:

- you have concerns that many local CCG prescribing policies for liothyronine (T3) are not consistent with NHS England policy and updated clinical guidance from the British Thyroid Association.
- the consequences of this are variations in patient treatment in local areas (postcode lottery) and extra costs caused by ineffective healthcare.
- briefly explain your circumstances i.e. you have had your T3 withdrawn without referral or you have been refused T3 without referral

FT3 below the reference range, consistent with the "low T3 syndrome," was found in 16/98 CFS patients compared to 7/99 controls.

Among other things they found possible evidence of (chronic) low-grade metabolic inflammation (ferritin They concluded, "*The most remarkable finding in this CFS case-control study was a higher prevalence of the "low T3 syndrome," attributable to a subgroup of CFS patients. Chronic low-grade metabolic inflammation was not convincingly noted. Low circulating T3 may reflect more severely depressed tissue T3 levels. The "low T3 syndrome" might be in line with recent metabolomic studies pointing at a hypometabolic state. It also resembles a mild form of NTIS (non-thyroidal illness syndrome) and the low T3 syndrome experienced by a subgroup of hypothyroid patients with T4 monotherapy. Our study needs confirmation and extension by others. If confirmed, trials with, e.g., T3 and iodide supplements might be indicated.and HDL-C). If confirmed, trials with, e.g., T3 and iodide supplements might be indicated.*"

You can find this study here:

<https://www.frontiersin.org/articles/10.3389/fendo.2018.00097/full#h6>

- you understand that there will be a members' debate on the cost and policy concerns, outlined in the report, and ask for their support

You can find your MPs contact details (telephone and email) here:

www.parliament.uk/mps-lords-and-offices/mps

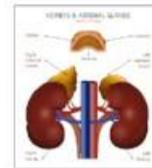
Please help us with this as it is the perfect opportunity to stop the CCGs withdrawing T3 from us.

In respect of the cost of T3, we are very disappointed to see that the two further manufacturers, Morningside Ltd and Teva Ltd placed their liothyronine onto the market at very, very similar prices. The prices have not changed since and this shows that competition is not working to bring the prices down. Thyroid UK will be contacting the Competition and Markets Authority and Jeremy Hunt MP about this.

We'll keep you informed.



Adrenal Insufficiency



The Increasing Trend of Thyroid Cancer

Update on Liothyronine Prescribing

Are you Taking your Levothyroxine Properly?

Join Us!

Our next issue, out soon, has articles entitled, "Adrenal Insufficiency", "The Increasing Trend of Thyroid Cancer" and two case studies of what's happened to two young children.

Members of Thyroid UK receive four issues of our magazine, Harmony, where you can read articles on all kinds of topics that relate to your thyroid health as well as discounts on supplements from Supersupps.

Supporting us by joining, helps pay for travel expenses for meetings that we attend and to pay for stationery that we use every day in the office when we send out information to people.

Joining us shows your support for what Thyroid UK does and enables us to continue the work that we do such as answering emails and posts and helping people on the telephone.

Please support us!

To join Thyroid UK please go to:

<http://www.thyroiduk.org.uk/tuk/membership.html>

£20 discount for Medichecks Thyroid Check UltraVit

Medichecks has £20 off the Thyroid Check UltraVit test for the month of April only. This is separate to the usual #ThyroidThursday discounts.

It's always a good idea to get your vitamin D tested as well as folate, ferritin and vitamin B12 along with your thyroid tests as these can impact on the thyroid system.

To take advantage of this offer go to:

<https://tinyurl.com/yc9hk49s>

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