

**PE1463/QQ**

Thyroid Patient Advocacy Letter of 4 March 2014

**Dear Convener and Members of the Petitions Committee**

**Thyroid Patient Advocacy (TPA) believes the relationship between the various UK Thyroid and Endocrinology Charities and the Royal College of Physicians is inward looking and incestuous and should be investigated as a matter of urgency.**

One **MUST** now questions **WHY** the Scottish Government took account of ONLY those submissions from the British Thyroid Association (BTA) the Scottish Clinical Biochemistry Managed Diagnostics Network (SCBMDN) and the Scottish Health Technologies Group (SHTG) when it is well known that these organisations have a close affiliation with the Royal College of Physicians (RCP). **WHY** have none of the other submissions been considered? This runs counter to the statement made by Michael Matheson that **ALL AVAILABLE CLINICAL EVIDENCE** should be taken into consideration.

**NOTE:** In the responses received, I cannot see one from the BTA as mentioned by Macheal Matheson. Would you please publish the BTA's response alongside the other submissions please.

Charities involved as authors in the policy statement on "The Diagnosis and Management of Primary Hypothyroidism"

- The Royal College of Physicians in particular its Patient and Carer Network and the Joint Specialty Committee for Endocrinology & Diabetes (**RCP**) (Reg. Charity 210508)
- The Association for Clinical Biochemistry (**ACB**) (No.863235)
- The Society for Endocrinology (**SFE**) (Reg. Charity 266813)
- The British Thyroid Association (**BTA**) (Reg. Charity 1119631)
- The British Thyroid Foundation (**BTF**) (Reg. Charity 1006391)
- The British Thyroid Foundation Patient Support Group (**BTF**) (Reg.Charity 1006391)
- The British Society of Paediatric Endocrinology and Diabetes. (**BSPED**) (Reg. Charity 283986)

"A Statement made on Behalf of .....". [http://www.british-thyroid-association.org/news/Docs/hypothyroidism\\_statement.pdf](http://www.british-thyroid-association.org/news/Docs/hypothyroidism_statement.pdf)

At first glance, you might think all the above associations must know what they are doing and have the medical evidence to back up their statements. Don't allow yourself to be drawn into this web. The above policy statement was written on behalf of all the above charities. These look to be 7 separate organisations. But take a closer examination and you will find each of these charities are working closely together – for their mutual benefit.

The British Thyroid Association (**BTA**), The British Thyroid Foundation (**BTF**) and the Association of Clinical Biochemists (**ACB**) were the authors of the 2006 UK Thyroid Function Test Guidelines – so they worked as one organisation. As the **BTF** Patient Support Group is run by the **BTF** – there is still only one organisation. The **BTA, BTF, and the ACB**, are all close affiliates to the **RCP**.

On the website of The British Society of Paediatric Endocrinology and Diabetes (**BSPED**) they have a statement saying they are **affiliated** with **RCP** and the Society for Endocrinology (**SFE**) (see below for the above organisations connections to **SFE**) – so, one could say there is only ONE organisation involved in the authorship of the policy statement on the diagnosis and management of primary hypothyroidism.

The Scottish Clinical Biochemistry Managed Diagnostics Network (**SCBMDN**) and the Scottish Health Technologies Group (**SHTG**) **that the Scottish Government** also have a close affiliation with the **RCP**

Then, we have Professor Graham Williams, who is the President of the **BTA** and Trustee of the Society for Endocrinology (**SFE**). Professor Graham Williams is also a Trustee of the British Thyroid Foundation (**BTF**).

The **BTF's** Director is also Membership Secretary of Thyroid Federation International (**TFI**) and also a Trustee of Thyroid Eye Disease Charitable Trust (**TED**).

All have joint meetings at The British Endocrinology Society (**BES**). Both **BTA** and **BTF** have a trustee in common and seem to keep abreast of **BES** meetings. However one could argue that this could be because it is all the endocrinology field of research. We can't find that **BES** is a Registered Charity, but there are similarities in their list of meetings and the way they are ordered 'Associates'. When we Google **BES**, and then click on **BES2009** - it takes us direct to the Society for Endocrinology (**SFE**) - <http://www.endocrinology.org/meetings/2009/sfebes2009/> .

You can also see a list of the **SFE's** Corporate Members: [ALMIRALL LTD](#) - [ASTRAZENECA PLC](#) - [BAYER SCHERING PHARMA](#) - [BIOSCIENTIFICA LTD](#) - [ELI LILLY AND COMPANY](#) - [FERRING PHARMACEUTICALS LTD](#) - [GENZYME THERAPEUTICS LTD](#) - [IPSEN LTD](#) - [MERCCK SERONO LTD](#) - [NOVARTIS PHARMACEUTICALS UK LTD](#) - [NOVO NORDISK LTD](#) - [NYCOMED UK LTD](#) - [PFIZER LTD](#) - [PROSTRAKAN](#) - [SANDOZ LTD](#)

And when you go back to the **BTA** site sponsors, you get a little more **BES** and the **BTA** show gratitude to the Clinical Endocrinology Trust (**CET**) who have generously sponsored the 'Pitt Rivers Lectures' at the **BES** Annual Meeting.

We also see on the **BTA** web site there is a link to the European Society for Endocrinology (**ESFE**) '...

[endo.org/membership/membership\\_countries.aspx](http://endo.org/membership/membership_countries.aspx) which shows the UK **SFE** President is Professor Julia Buckingham.

<http://www1.imperial.ac.uk/medicine/people/j.buckingham/> Shows Julia Buckingham's involvement with **Big Pharma** and the **SFE** -

- British Pharmacological Society: President, 2004 to date
- The Journal of Neuroendocrinology: Editor-in-Chief, 2004 to date
- BioScientifica Ltd, Society for Endocrinology: Chairman 2002 to date
- British Society for Neuroendocrinology: Member of Council, 2004 to date
- Member of the Board of Governors, St Mary's School, Calne, Wiltshire, 2003 to date

We see that **BioScientifica Ltd** - of which Julia Buckingham' is Chairman is the 'company' section of the **SFE**.

Then there is the 'Clinical Endocrinology Trust' (**CET**) - are they connected too?

Yes!

The Clinical Endocrinology Trust. (**CET**) - **Registered Charity 288679**

**Trustees:**

Mrs Elizabeth Whelan

Dr J S Bevan

Prof. A P Weetman

Prof J R E Davis

Prof. Jayne Agnete Franklyn

There are no other charities displayed on the **CET** details for Professor Jayne Agnete Franklyn MD PHD FRCP. Yet she IS a Trustee of the **BTA** Charity 1119631 and also a Trustee of the **BTF** Charity 1006391. Why has she not declared these?

All those Big Pharma are on the corporate members list of the **SFE** - and at the bottom of the **BTA** site also.

ALL the above organisations/associations are close affiliates to the **Royal College of Physicians**.

We believe that the above organisations could be the same organisations involved in every meeting where guidelines and recommendations with the **RCP** are involved.

<http://www.acb.org.uk/docs/Hypothyroidism%20Statement.pdf>.

No other patient organisations or medical practitioners who are diametrically opposed to this policy statement have been approached for their views.

If there are laws regarding transparency of charitable organisations, then surely such laws will apply to the **RCP**. In the **RCP Annual Report and Accounts 2007 – it reads:**

- *“We need to know the transparency requirements of a charity to give out the names of those sitting in on committees such as those for the guidelines.”*

Yet – the **RCP** have refused to publish the names of those who were on the working party involved in the policy statement on ‘The Diagnosis and Management of Primary Hypothyroidism’.

Is the **BES** an umbrella organisation for **ALL** endocrine societies? That might make sense. But, if you Google British Endocrine Society **BES** - it always takes you to the **SFE** website - so why a separate name? The **BES** has also the same address as the **SFE**.

The **BTA** is the member organisation for the professional Endocrinologists. The **BTF** is the BTA’s patient organisation. How many Endocrinologist are members of **BTA**? If their members are composed of Endocrinologists, that means they will be all members of the **SFE** - which is sponsored by **Big Pharma**. Who accredits them?

There’s a statement from an old newsletter from the **BTA** to their members.  
<http://www.endocrinology.org/sfe/endocrinologist/end06207.pdf>

- *“Numerous Web sites are devoted to this issue, some of which seem to be most convincing but are misleading. These need to be monitored, and action taken if and when appropriate. Look around for them on the Web, and you will see what your patients are reading!”*
- *“The **BTA** also has an important role in the development of evidence-based national guidelines. There are currently two active groups. A multidisciplinary group has been working on national guidelines for the management of thyroid cancer. Following good progress, the guidelines should soon be available.”*

However in the same letter, it states...

- *“The second group is addressing guidelines for the use of thyroid tests. These are also important for many reasons, not least of which is the current (ill-advised) practice of using TSH alone as the first-line test for thyroid dysfunction.”*

Written by Pat Kendall-Taylor (**BTA**)

The same lady’s profile on a networking site – where there are some familiar names here ?

[http://www.biomedexperts.com/Profile.bme/690663/Pat\\_Kendall-Taylor](http://www.biomedexperts.com/Profile.bme/690663/Pat_Kendall-Taylor)

The British Society for Paediatric Endocrinology and Diabetes. (**BSPED**) have a statement on their website as follows

- *“The charity works closely with national agencies for paediatrics and is affiliated with the **RCPCH, BES, Royal College of Physicians** and the **Society of Endocrinology**”*

So...it appears that (for the moment, until further investigation takes place) we have the **BTA, BTF, BES, SFE, RCP, BSPED, CET, SCBMDN and SHTG** who are all, apparently working together to serve their common interests – but they are failing to serve the interests of the patient.

We would request that the Scottish Government seek the views of Thyroid Patient Advocacy and all UK thyroid charities who have many members in Scotland and elsewhere, throughout the UK.