

Thyroid UK
Annual Report and Accounts
For the Year Ending 31st May 2008

Dated: 1st November 2008

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“In the United Kingdom alone, an estimated 4.5 million people have a thyroid problem out of a population of 60.4 million. a further two million people are believed to have over or underactive thyroid glands that remain unrecognised, although these cases are often mild.”

Alan L. Rubin, MD and Dr Sarah Brewer

“About 1 in 50 women, and about 1 in 1000 men develop hypothyroidism at some time in their life. It most commonly develops in adult women, and becomes more common with increasing age. However, it can occur at any age and can affect anyone.”

Patient UK

We are very pleased to bring you our very first Annual Review. Although Thyroid UK has been in existence for several years, we have never had a proper structure. We reviewed our strategic objectives in May 2008 and now have a strategic plan for 2008-2011. Having a proper structure enables us to see much more clearly the way forward and we are grateful to Pat Endicott for joining us and giving us the knowledge we needed for this to happen.

The main reason Thyroid UK was formed was to help people who have all the symptoms of thyroid disease, mainly hypothyroidism, but who have been told they have normal thyroid function tests.

We know that we have helped many people already to become well again and to take part in normal family life. However, since the latest Guidelines for the Use of Thyroid Function Tests published in by the Association for Clinical Biochemistry, the British Thyroid Foundation and the British Thyroid Association, our job has become even harder.

On top of that, there are many people who have been completely well on a certain dosage of thyroid hormone, whose doctors have suddenly started reducing their dosages, possibly due to the above mentioned Guidelines, thereby making them ill again.

Thyroid UK will work hard over the next few years to achieve our aims and objectives so that changes can be brought about in the diagnosis and treatment of thyroid disease.

This first annual review actually covers more than one year. It covers about three years work altogether but it just happens that the projects were all achieved in 2008! We wanted you to see what we had achieved and what our future objectives are. Our next Annual Review will be in accordance with the requirements of both Companies House and the Charity Commission.

1. Thyroid UK’s Trustees, Committee Members and Advisers

Trustees (Executive Committee)

Lyn Mynott – Chair

Jane Bull – Secretary/Treasurer

Dr Barry Durrant-Peatfield – Adviser

Ms Diana Laxon

Associate Committee Members

Peter Warmingham
Barbara Reed
Judy Parmenter
Pat Endicott

Medical Advisers

Dr Barry Durrant-Peatfield
Dr John Lowe
Dr Sarah Myhill
Dr Jacob Teitelbaum
Dr Bo Wikland
Dr Kent Holtorf

Chief Executive: Lyn Mynott (as from 1.11.08.)

Office Administrator: Miss L Warvill

Office Assistant: Mrs J Turner

1. Thyroid UK History

Thyroid UK was originally started in the home of its founder, Lyn Mynott, in 1998 under the name of Thyroid Action Group, holding monthly meetings to help people in the area.

In 1999 the BBC programme, Watchdog Healthcheck came to her home to make a short report about what she was doing and the response was so huge that she knew something was not right in the diagnosis of hypothyroidism.

Over the next year, she found other people with similar problems who wanted to help so she set up a committee in 2000, changing the name in 2001 to Thyroid UK.

2. Thyroid UK's Structure, Governance and Management

Thyroid UK is a company limited by guarantee. The registered office is 32 Darcy Road, St Osyth, Clacton-on-Sea, Essex CO16 8QF. The company's registered number is 6254073 and the charity's registered Number is 1125270. The members of the company are the Executive Committee. Another class of membership is open to subscribers to the Thyroid UK newsletter

Thyroid UK will be changing the structure slightly in 2009 – we will be changing the Committee's name to Board of Trustees and there will be different classes of membership, one being an open membership of the Friends of Thyroid UK. Membership of the Friends of Thyroid UK will include a quarterly newsletter.

Trustees are elected at the AGM and can be re-elected by the Trustees. At the moment Associate Committee Members can become Trustees after a period of two years but this will change in 2009, when there will be no time period for appointing new Trustees.

Thyroid UK is just beginning to put policies in place for Code of Conduct, Expenses, Conflict of Interest, Working with the Companies (including the pharmaceutical industry), Complaints etc.

The Executive Committee delegates the day to day running of the charity to the Chief Executive who is supported by an Office Administrator and an Office Assistant who both work part time.

Thyroid UK Trustees have all had some experience of having to deal with thyroid disease – they either have the disease themselves or a member of their family has a thyroid or related problem. All Trustees will be asked to sign a Code of Conduct form and complete a Declaration of Interest form.

The Thyroid UK Patrons have all had thyroid disease.

3. Thyroid UK's Mission, Vision, Values and Objectives

Our Mission is:

"Providing information and resources to promote effective diagnosis and appropriate treatment for people with thyroid disorders in the UK"

Our Vision is:

- To be the primary source of independent, accredited information on thyroid-related disorders in the United Kingdom
- A world where the patient's needs are paramount
- A world where patients with thyroid disease will have the choice to be treated according to their individual needs

Our Values are:

- To be open, honest, ethical and accountable and to work productively with others in the pursuit of quality treatment for patients
- To put the interests of people with thyroid disorders first
- To value people as individuals
- To respect the right of individuals to be involved in and knowledgeable about their illness and treatment options
- To value the need for open and free access to independent and accurate information both at the time of diagnosis and thereafter
- To encourage people to take control of their own health and well-being
- To appreciate the skills, expertise and commitment of our staff and volunteers

Our objects are:

The relief of sickness of persons suffering from thyroid disease and related areas, for the benefit of the public, particularly but not exclusively by:

- (a) providing information and support to sufferers of thyroid disease
- (b) promoting public awareness in regard to thyroid disorders
- (c) acting as a resource centre and disseminating information
- (d) encouraging scientific research for the education, alleviation, care,

- (e) treatment and cure of thyroid disease
- (e) raising funds needed to achieve the stated objectives.

4. Thyroid UK's Achievements

Thyroid UK now has over 14,000 contactees – people who have contacted them for help and the website had almost 66,500 unique visitors last year. We have a Support Network – five Thyroid UK groups; five Independent Support Groups; twenty five telephone helplines and eight email Support Networkers. We have a Medical Advisory Panel for questions from both our own Committee and the public. A quarterly newsletter is also produced for an annual subscription fee. We provide leaflets; an Information Pack on thyroid disease and various other Information Packs. We include case studies on our website and in our newsletter, as well as reports on up to date research studies with regard to thyroid disease.

Thyroid UK is a member of the James Lind Alliance, a non-profit organisation which is concerned about the uncertainties of the effects of treatments in health care. Thyroid UK is also a member of National Voices (previously Long Term Conditions Alliance), an umbrella group for national voluntary organisations representing users of health and social care in England. They work with policy-makers in Westminster and Whitehall to make sure that the voices of patients, carers and service users are heard. Thyroid UK is also a member of the Patients Information Forum.

Thyroid UK has worked with IWDL – now Genova – to enable our members to get more tests and gain their own results. Patients cannot normally obtain their own test results even though they paid for them themselves.

Thyroid UK was on the Working Group for the Government's Health Accreditation Scheme ensuring that documents had to be balanced stating pros and cons of treatment. Thyroid UK has also been accepted, out of 120 groups who applied, to be on the Pilot for this scheme and so is now working with the Department of Health to test it. We will be updating all of our information in readiness for the Accreditation. This updating will include new leaflets on various aspects of thyroid disease.

We have been involved in workshops regarding the Choice agenda; conferences in respect of Information Prescriptions and attended several INVOLVE conferences and workshops to show that we firmly believe that patients should be involved in their health care. Lyn Mynott has also attended several conferences in respect of the new Local Involvement Networks (LINKs).

With funding from subscribers, members of the public and one main anonymous donor, Thyroid UK has designed, obtained Ethics Approval and is running a study into blood and urine testing for thyroid disease. All the patients have been tested now and controls have started being recruited.

Lyn Mynott gave a presentation at the University of East Anglia about our study to show how patients and the public can design, obtain Ethics Approval and run a research study. She has also given talks to members of the public and fibromyalgia groups about the different aspects of thyroid disease, particularly about testing and treatment.

After a lot of hard work, Thyroid UK finally became a Registered Charity in August 08.

Thyroid UK ran a Medication Survey in 2008, sponsored by Goldshield Pharmaceuticals which showed that many people were not at all happy with the blister packs used for thyroid medication and

also that many people wanted natural thyroid hormone as a treatment for hypothyroidism. It also showed that some NHS doctors are, in fact, prescribing the natural thyroid hormone to their patients.

Thyroid UK instigated Thyroid Awareness Week for the third Saturday in October and other thyroid groups have now taken this on board.

Thyroid UK has recruited more volunteers to help the Executive Committee achieve their objectives.

Lyn Mynott has taken part in several interviews with journalists to promote Thyroid UK and the work that they do, providing case studies to show different aspects of diagnosis and treatment.

5. Fundraising

We have not had a lot of time to spend on major fundraising. However, we have spent some time putting together a proposal to Awards for All and we are at present waiting to hear whether we have been successful.

6. Publicity

Thyroid UK has joined media websites in order that we are aware as soon as possible of journalists wishing to write articles about thyroid disease and in need of case studies.

7. Office Premises

At the moment the office is in the home of Lyn Mynott, the Chief Executive, which is not ideal, bearing in mind that we have two staff who come in at least three days per week. However, with funding from a donor a log cabin was built. Lyn Mynott's family and friends erected the log cabin free of charge and this is now almost finished. Donations from subscribers and members of the public have enabled us to carpet the log cabin and buy some items needed to furnish it. We have applied for a grant to purchase larger items of furniture and computer equipment and we hope to take up residence soon.

8. Website

The Thyroid UK website is run by a person who was helped by Thyroid UK and who allows us a very much reduced rate of payment. The information on the website is almost the same as the information in the Information Pack so that people can get this information free. There is also a latest news section on the website. The website will be reviewed and updated in 2009.

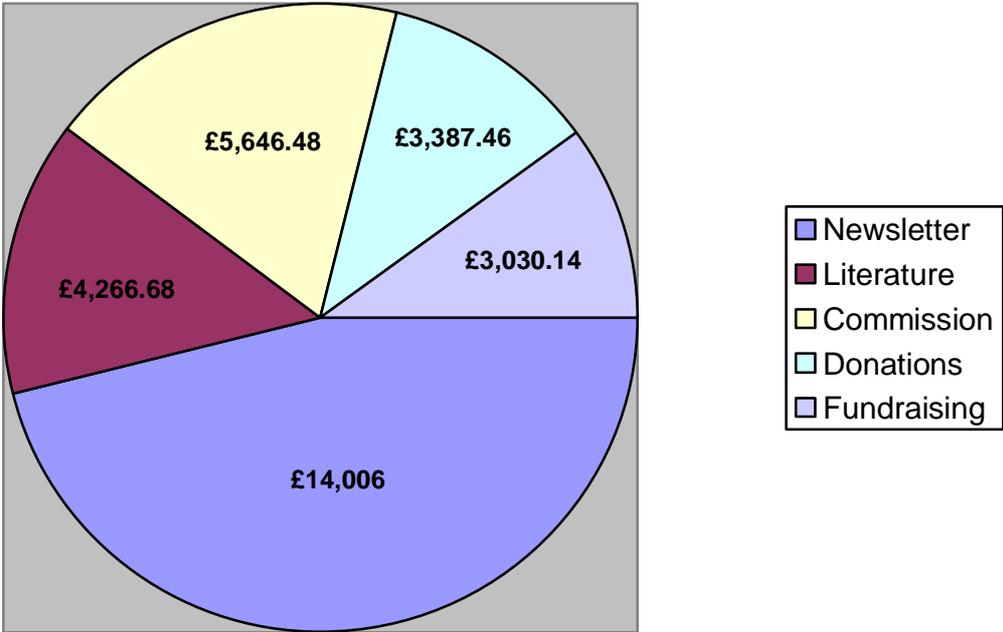
9. Financial Review

Due to technical problems, Thyroid UK did not trade as a limited company by guarantee until 1st June 2008 so there are no annual accounts for the limited company for the period up to 31st May 2008.

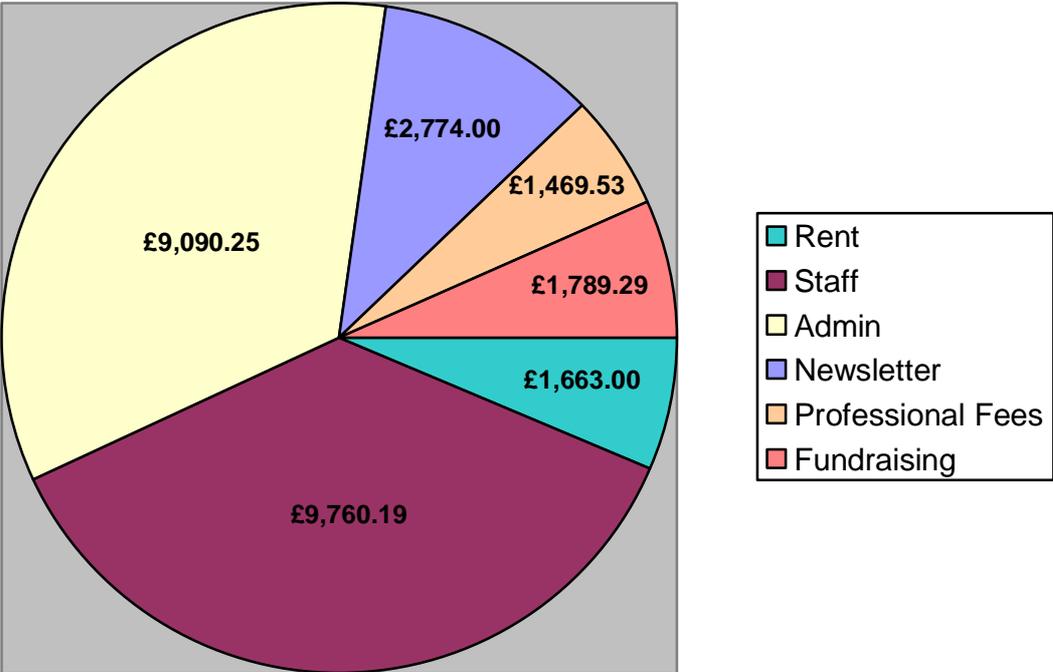
We do, however, have accounts for the not for profit organisation up to 31st May 2008 with most monies coming from the sale of the Information Pack and newsletter; commission from test sales with Bio-Vitality, Genova Diagnostics and Red Apple Clinic. We managed to raise funds from Amazon.com, postage stamps, recycling, the Easyfundraising website, the sale of pens, key-rings, wristbands and Christmas

cards. Even though these do not make very much profit, it all helps. We are very grateful for the donations we have received, especially the large donation for the log cabin from a subscriber who wishes to remain anonymous.

Income



Expenditure



Thyroid UK has two bank accounts – one for the day to day running of the organisation and the other for Projects. Both bank accounts are reconciled weekly. A financial summary is provided at Committee Meetings.

There will be full accounts available next year.

10. Plans for the Future

Thyroid UK has put together a Strategic Plan for the next three to five years. Projects include:

- Achievement of the Accreditation for Health Information
- Informing doctors and endocrinologists of our achievement and encouraging them to put our name on all Information Prescriptions given to newly diagnosed patients of thyroid disease
- Furnish the log cabin
- Recruit new Trustees and volunteers
- Review and update website
- Enable online payments for our products and services
- Podcasts on our website on a variety of topics in relation to thyroid disease
- Guidelines and training for our Support Networkers
- New telephone system
- Join Telephone Helpline Association
- Conference in 2009
- Seminars across the UK
- New design Thyroid UK News
- Surveys/polls on various topics relating to thyroid disease
- Health on the Net Award

All of these projects will mean that we will reach more people who are, as yet, undiagnosed and probably only just managing to take part in family life – something Lyn Mynott remembers was so dear to her.

“I can remember taking my very young son to a baby gym class and the only way I could deal with this was by propping myself up against the wall near to where he was using the gym equipment. I was in so much pain and people were looking at me as if I was mad. I set up Thyroid UK to stop this kind of thing from happening to other women.” Lyn Mynott

Thyroid UK would not be able to continue without the support it receives from our Board of Trustees, Medical Advisers and volunteers who have given their time; our subscribers to the newsletter and individuals who have given their money. There are so many people who have helped us one way or another – too many to list here although I would like to say a special thank you to Louise, my secretary, without whom I'd be in a complete mess, Jane Bull and Pat Endicott, who have always been there for me and the rest of the Board of Trustees for putting up with my constant emails and requests for help!

Finally, I'd like to say a big thank you to all those who have contacted us – we wouldn't be here without you. Thank you so much for your support. I am sure that 2009 will be a really good year for us!