

Thyroid Federation International

Established in September 1995 in Toronto, Canada

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Member Organizations

Our member organizations now number 21, representing 16 countries. The names of the organizations and their current addresses are given on page 16.

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From the Editor's Notebook

Unfortunately, I was not able to attend the TFI conference held last year in Istanbul.



JRB, Editor

But Beate Bartes was! A new member of TFI, she has already done sterling work as secretary at the conference. She has also helped me greatly in putting together this issue of ThyroWorld. Besides reporting on the conference highlights, she has written an article about her Bulletin Board (*see page five*).

There were fewer member organizations at this year's conference. Distance, expense and personal circumstances all played a role. It has made us realize how important it is to keep in touch about our activities throughout the year, not just at our annual meeting. TFI's member organizations are spread out far and wide around the world from Australia to the USA. The common bond is our concern for "those affected by thyroid disorders."

Most of us have directly experienced the vicissitudes of thyroid disease. In this, we have an advantage over our doctors. We know what it's like to feel the depths of fatigue and depression, the despair of "hypo hell" and of devastating eye problems. Our doctors know the scientific and medical side of thyroid disease; we know the physical and emotional one. That's why we need to share information with our professional colleagues and with each other. More and more, TFI is being invited to professional conferences – recognition that our information and support are valuable.

Indeed, some remarkable projects and activities are being tried out – TSH screening in Canada, rehab camps in Finland, a thyroid booklet for children in Denmark, a marathon in Scotland. A project in one country may lead to a similar undertaking in another. Sometimes all it takes is permission to translate – freely given.

I, for one, missed meeting old friends and colleagues, the camaraderie and the 'feel' of the conference, displaying our information in several languages at our booth and meeting new people interested in learning more about TFI.

So keep in touch, dust off your dancing shoes and hope to see you in Argentina. 🍷

June Rose-Beaty
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President's Message

Many people around the world are devoted to making life better for thyroid patients. Among them: thyroid specialists, healthcare professionals and workers, the patients themselves and all those who work as volunteers in patient organizations. Their work is extraordinarily important in today's society.

Here I am, sitting on my veranda in the lovely spring sun in Sweden, writing this message and thinking — almost dreaming — of gathering us all together to share our experience and knowledge ... to collect all the good ideas and information coming out of such a meeting and use this wealth for the benefit of all those suffering from thyroid disorders all over the world. It would be lovely, wouldn't it?

But it is more than just a pipe dream. Since its beginning in 1995, the Thyroid Federation International has begun to turn dreams into reality especially during the last five years.

It takes time, however, to gain awareness of and acknowledgement for what we are doing. We have had to prove that we are serious in our efforts. Today we are gaining respect from professional organizations such as the European Thyroid Association and the American Thyroid Association. Where once we used to plea for co-operation, ours is now being sought – a huge step forward, but many more to take.

At our annual meeting last September in Istanbul, held in conjunction with the ETA conference, one issue discussed was helping patients and doctors in other countries start patient organizations with the support of TFI. A positive result was that a number of countries such as Turkey, Greece, New Zealand, China and Mexico have shown interest in starting patient organizations and in becoming members of TFI.

Our continuing commitments remain:

- to raise awareness of thyroid disease among health care professionals and the general public all over the world
- to have the value of patient organizations well recognized and to promote the benefit of professional and patient organizations working together
- to follow ongoing thyroid research and its results and to make this information available to patients

Many important issues directly affect the patient.

- Iodine deficiency – a condition still existing in many countries
- Thyroid disease and pregnancy – the importance of careful and accurate control during pregnancy
- TSH normal range – the confusion caused by the use of different laboratory measurements in different countries
- T3 treatment – useful or not?

Finally, why do many thyroid patients not feel well in spite of accurate treatment and normal hormone levels? This is an important question not to be neglected. The very fact that many patients on thyroid hormone medication don't see themselves as healthy is indeed disturbing.

I hope that we will see some new members and, of course, all the present ones at the meeting of the 13th International Thyroid Congress in Buenos Aires October 30 - November 4. These meetings are excellent opportunities to discuss and exchange experiences and ideas for the work within our organizations.

There are many challenges ahead. More than enough to share. Please join us in our work for the benefit of all thyroid patients around the world. 🌍

*Yvonne Andersson, President
Thyroid Federation International*



*Yvonne Andersson,
President*



*TFI Family: France, Denmark, Sweden, United Kingdom,
Finland, The Netherlands, Canada*

ThyroMobil Down Under



When we last had word in 2003, Merck's ThyroMobil was preparing to board ship for Australia. It was to take part in a national study to determine the status of iodine nutrition. Now two years later, the study has been completed with some interesting and surprising results. Whereas earlier it had been thought that only the island state of Tasmania was deficient in iodine, it now appears that there is a much wider range of deficiency across the country.

The study was conducted by NINS* and coordinated by ACCIDD* with Professor Creswell Eastman and Dr. Mu Li directing operations. The subjects were school children aged 8 – 10 who took part voluntarily in the survey that covered all states and visited some 19 primary schools. As ThyroMobil trundled its way across the outback, covering more than 25,000 kilometers, the goal was to test some 300 – 400 children in each state.

Two methods of testing were used: urine sampling and ultrasound examination. From the urine samples, the daily iodine intake can be measured while the ultrasound examination indicates the size of the thyroid gland. ThyroMobil, a unique vehicle, is well equipped to play its part as it has both refrigeration facilities and ultrasound equipment as well as a highly trained and experienced staff.

Now that the survey has been completed and the results compiled, it appears that iodine deficiency has emerged across the country, most marked in the eastern states. The cause – lack of iodine in the average Australian diet. For more than four decades, the principal source of dietary iodine has been milk and other dairy products. A few years ago, however, the dairy industry



Professor Eastman, Dr. Li and children with ThyroMobil.

switched from iodine containing sanitizers to chlorine based ones with a dramatic fall in dietary iodine intake. Unfortunately, less than 20% of Australian households purchase iodised salt and the food industry does not use it in food processing.

Professor Eastman states that the absence of iodine is a serious concern for pregnant and breastfeeding women and young infants. "Iodine Deficiency Disorder in children can mean lower intelligence levels with long-term learning and physical development difficulties."

But the positive side is that IDD can be prevented and controlled through adequate iodine in the diet. The desired outcome of the study is to have State and Commonwealth governments pass legislation for mandatory iodisation of all salt sold for household use and in the commercial production of food.

Although the expedition had a serious purpose, it must also have had some lighter moments. Just imagine all those children lining up to give their urinary all (or their wee bit) for science!

Good on you ThyroMobil and all the mates that took part in this remarkable venture. 🍷

The contribution of volunteers from the Australian Thyroid Foundation is greatly appreciated and made the conduct of the survey possible.



*Professor C. Eastman,
Patron of ATF*



Professor Eastman and "thumbs up" friends from the outback.

* NINS National Iodine Nutrition Study

* ACCIDD Australian Centre for Control of Iodine Deficiency Disorders

Bulletin Board « Vivre sans thyroïde », France

“Life without a thyroid gland”



Beate Bartes is the newest member of TFI, joining in September 2004. Along with her, came her Bulletin Board. Here she explains the aims of “Vivre sans thyroïde” – Life without a thyroid gland. She describes how it came into being, how it is organized and what it has meant in her life.

Help from Home

I come from Hamburg in the North of Germany but since 1978, I've been living in the south of France with my French husband and our three daughters; I work as a translator. In 2002, I was treated for thyroid cancer with a thyroidectomy and radioiodine. During this time, I found a lot of help on a German bulletin board, “Ohne Schilddrüse Leben” (www.sd-krebs.de), created by a patient. I found it very useful to be informed, to know what would happen at the hospital, how you feel during hormone withdrawal, what you can do to feel a bit better and to hear from patients who had just finished this treatment and were well again. These “conversations” helped me a lot during my stay in hospital and in my discussions with doctors, because I could understand what they were talking about (TSH, T3, T4, radioiodine), and ask them the right questions.

BB On Line

Once I had finished the radioiodine treatment and had come out of “hypo hell” again, I decided to create the same sort of web site in French. I'm quite good in writing, but I didn't know anything about programming, HTML code and all those mysterious terms. Luckily, the German webmaster Harald helped me a lot, via email!

So my Bulletin Board went online in October 2000, starting with just a few persons. In the beginning, I answered all the questions on my own, but soon some of the regular visitors started participating and sharing their experiences. During the first months, there were only a few new messages a day, but then the forum grew bigger and bigger until it now has some hundred visitors a week, 130,000 “hits” a month (more than 200,000 since its creation), it has over 762 registered members and an average of 27 messages a day. In May 2004, it was totally reshaped (PHP), and now

has several subgroups for features such as autoimmune disease, cancer, hormonal treatment, patients' rights, as well as subjects other than thyroid.

Questions and Answers

To help “newcomers” find the relevant information as quickly as possible, and to avoid repeating the same answers to the same questions all the time, I created different features: “Frequently asked questions such as, “How long does it take to get out of hypo hell? Without a thyroid gland, can I get pregnant? My baby was born without a thyroid gland, can she have a normal life?” I also created a list with links to other web sites explaining the thyroid gland and its dysfunctions as well as a list of “member profiles” where regular users can present themselves and their disease. There is also a live chat feature. The Bulletin Board operates mainly in French but can handle questions in English and German too.

Faithful Helpers

Many users remain faithful to the forum even after their own problems have been solved. They remember how much others had helped them when they first arrived. They wish to continue helping others by sharing their experiences. There is a heartwarming solidarity and mutual willingness to help each other – people who have been through this kind of problem know how others feel!

Worldwide Sharing

A bulletin board on the Internet, even if it is only “virtual”, with people from all around the world (France, Belgium, Switzerland, Canada, Morocco, Algeria) is just like people meeting in a real-life support group, sharing their experiences, giving advice and comfort. For patients, especially newly diagnosed ones, it is very important to discuss their concerns not only with doctors, but with other patients affected by the same disease, to see that they are not alone, that many other people have the same problems and fears, but that solutions exist.

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Dr. Robert Volpé — In Memoriam

Members of the Thyroid Federation International were saddened by the death of Dr. Robert Volpé on April 19 of this year.

A world renowned and respected endocrinologist, he was highly regarded by colleagues and students alike and well loved by his patients. He often said that he learned more from them than they from him. He was an active member of the American Thyroid Association for forty-five years and Medical Adviser to the Thyroid Foundation of Canada, his home organization, for more than two decades.

He gave strong support to the work of these organizations. Although his association with TFI was short, we were indeed fortunate to have had

the benefit of his wisdom and counsel in its early years. Among his numerous awards was the Order of Canada, that nation's highest honour.

He was a genial man who loved company and delighted in telling a good story or joining in a singsong. Many members of The Thyroid Foundation of Canada will have memories of those happy times. But there were sad times as well: the death of his dear wife Ruth greatly diminished him. Dr. Bob was TFC's mentor and friend, supporting our goals and guiding our course. He will be sorely and truly missed. 🍷

*"Better loved ye canna be,
Will ye no' come back again."*

Bulletin Board (continued from page 5)

If thyroid surgery is an option, it is very reassuring to discuss the procedure with other patients who have had the same intervention and hear that they had no particular problems and recovered very quickly. Many patients, struggling with the psychological side-effects of hypo or hyperthyroidism, feel very lonely and isolated, because their family and friends know little about thyroid disease and believe that the person just needs to "pull yourself together". It is very reassuring to hear that other patients feel the same, and to learn that this feeling of isolation will lessen and understanding will increase once the hormonal treatment is correctly balanced.

Up, up and away ... floating over Turkey



... in my beautiful balloon.

Projects Ahead

I've always been interested in international cooperation. I find it very important to talk with patients and doctors in other countries to compare how thyroid problems are treated, to get new ideas and to help each other. One such project is to edit a book with stories from patients about their thyroid experiences with short articles by doctors to introduce the various chapters. We hope to finish the project by summer of this year. Another step in cooperation is the invitation I received to attend a cancer symposium in Paris where I hope to gain lots of interesting information that will find its way to the Bulletin Board.

A Rewarding Experience

I first met the TFI group during the Edinburgh meeting in 2003 where I represented the French thyroid patients' association AFMT. Shortly thereafter, my Bulletin Board became a TFI member in its own right in September 2004. For me, it has been a rich and rewarding experience – I have never felt so useful. I hope that all together, we will manage to increase public awareness about thyroid problems, ease the relationship between patients and doctors and improve thyroid disease treatment all over the world. 🍷

*Beate Bartès
Toulouse, France*

<http://thyroide.free.fr>
www.forum_thyroide.net



Triple Winners: WWW

The Thyroid Foundation of Canada has a new President, a new organizational structure and a new vision. Part of President Ted Hawkins' new strategic plan is to seek out partners for educational projects. A golden opportunity presented itself in the autumn of 2004 for just such a purpose when Abbott Laboratories offered an unexpected and unrestricted grant. The only catch was that the project had to be completed by the end of November. Here is Ted Hawkins' account of how the venture played out.

It was full steam ahead to meet the deadline. The project was quickly identified: TSH screening. The goals were set: to raise awareness of thyroid disease, to identify potential patients (and those in need of monitoring) and to provide support to concerned persons. Two areas without ready access to a thyroid specialist and thousands of miles apart, were chosen: Barrie, Ontario and Victoria, British Columbia. Barrie is a small town in central Ontario about an hour's drive north of Toronto; Victoria, the capital of British Columbia, is on Vancouver Island, the Pacific coast.

In Barrie, our partner was the Royal Victoria Hospital which provided the facilities and services. Their team brought a high level of cooperation, caring and expertise to the project. In Victoria, our partners were the James Bay New Horizon Centre which provided the facilities and ThyroTec, Inc. the manufacturer of *ThyroTest*, a finger prick thyroid blood test. It has been approved in the USA and, in Canada, test experience and information is being gathered at the request of the Health Protection Board.

The Barrie experience was a great success. The weather cooperated and the turnout was high. We did radio interviews about the Foundation, and one live TV interview with an additional TV taped interview that was released to support the Saturday session. We spoke with over 500 people in two days; 248 blood tests were done on Friday and a further 174 on Saturday for a total of 422.

In Victoria, similar excellent media coverage was arranged and an additional 400 people turned up for information or the test.

Combining the two experiences in Barrie and Victoria, over 800 people were reached with 565 taking the TSH test. Of this 800 total, 8% were outside the normal range, an unusually high

number. The range used was 0.5 – 5.5. Fortunately, few were of astronomic proportions. The results have since been received and those outside the range have been informed of their readings and advised to consult their physician.

Through the media of print, radio and television, our message had the potential to reach 300,000 people and the screening program proved to be an excellent medium for that message.

From this opportunity to talk with patients, those who suspect they might have a thyroid condition and those who are concerned for others, I believe that the Foundation is more relevant and needed than ever. The project gave us the opportunity to work with multiple partners to a successful outcome. For all those involved, it was a triple win: a win for us, a win for our partners and a big win for thyroid patients. 🍀

Ted Hawkins, President TFC



A Sad Spring

The Thyroid Federation International thinks of itself as a family. In times of need and sorrow, families come together to share grief and to give their support and love. We all share in the sad death of Lisa Andersson, the dear little daughter of Yvonne Andersson, TFI's President. Lisa died in May, just as spring was coming with hope for her of a new life after a long time of illness. A courageous little girl, she had borne many restrictions in her young life with great fortitude while waiting and hoping for a donor heart. She also showed great generosity of spirit in making arrangements to donate her own organs so that some other child might benefit. The death of a child is heart-breaking. The sorrow of Yvonne, her husband and family is beyond words. We can only reach out to them with our thoughts, prayers and love.

Our sympathy and love go out as well to Bente Julie Lasserre whose dear mother also died in May, only a few days apart from Lisa. There is comfort for Julie and her family in knowing that their mother had lived a full life, well loved by her family and friends.

All members of the TFI family and friends are saddened by these partings, always to be linked in our memories. 🍀

All About Thyroxine:

Jim Stockigt is Professor of Medicine at Monash University at the Alfred Hospital, Melbourne, Australia and is in consulting practice at Epworth Hospital, Melbourne. He is the author of over 120 papers on thyroid disorders, thyroid hormone action and testing of thyroid function. He has also contributed chapters to current editions of classic texts on endocrinology. With over 100 million people worldwide taking thyroid medication, his concerns about thyroxine are pertinent and timely. In October 2004, he gave a review presentation on Tests for the Bioavailability of Thyroxine at the American Thyroid Association. We present here a summary of his remarks.



Dr. Jim Stockigt

of over- or under-treatment. Highly sensitive TSH assays now allow important dosage differences to be detected in a way that was impossible until about ten years ago.

There has been sufficient doubt about the equivalence and interchangeability of various preparations for the US Federal Drug Administration to require new drug applications to be filed between 1997 and 2000 for the various commercial preparations of thyroxine. Not all manufacturers were enthusiastic about doing this, especially as no “gold standard” of bioavailability or bioequivalence could be specified. Emphasis has

With over 100 million people worldwide taking thyroid medication, ...

A Little History

Effective thyroid replacement was first given in 1891 by injecting extracts from the thyroid glands of sheep. Tablets of thyroid extract from this source remained the standard preparation until synthetic L-thyroxine sodium became available about 1962. Since 1970, synthetic thyroxine has become standard therapy. The points in its favour are its purity, supposed stability and ease of standardization compared with sheep thyroid extracts. Some difficulties, however, still need to be resolved. About 1982, a change in the method of standardization led to increased potency so that optimal dosage needed to be revised downwards. In the fifteen years from 1982 to 1997, there were repeated problems with variable tablet content, as well as uncertain shelf-life, stability and absorption. On a number of occasions between 1987 and 1997, synthetic thyroxine preparations were recalled for sub-potency. These issues generally received little publicity so that clinicians and patients have sometimes been caught unawares by technical problems in formulating thyroxine.

More Equal than Others?

We generally presume that optimal treatment with thyroxine can be easily and safely given. Thyroxine, however, has a narrow therapeutic index, with well recognized adverse consequences

generally been on studies of absorption as an index of bioavailability, using volunteers with normal thyroid glands, but this technique is beset with problems. Ingested thyroxine is indistinguishable from the hormone already in the body, a problem addressed by giving an abnormally large dose that “swamps” the normal concentration. In response to such a dose, however, serum TSH decreases so that thyroxine production from the study subject’s thyroid will also decrease. There is no established way of correcting for this decreasing baseline, which will lead to under-estimating the effect of the thyroxine load. Furthermore, the large test dose of thyroxine alters occupancy of plasma binding proteins and thus increases removal of thyroxine. A recent study showed that 25% differences in potency, or absorption, are not detectable by studies of this sort! Thus, products that differ in potency by up to 25% (sufficient to result in significant therapeutic error) could be falsely classified as equivalent! (Many readers will appreciate that failure to show a difference in statistical terms, customarily $p > 0.05$, does nothing to demonstrate equivalence).

Uncertainty, confusion and dispute have followed against a background of competition for market share, arbitrage of products and companies, as well as the emergence of less expensive and less profitable generic

Some Current Issues

preparations, that are attractive to health insurers. Complex and rather opaque tables now attempt to define which of the various competing brands of thyroxine are, or are not, equivalent.

Changing Brands: a Word to the Wise

Because current studies of thyroxine absorption still allow at least 25% variation in potency to go undetected, there can be important differences between various brands that may be classified as equivalent. If the medication in question were aspirin, such a difference might be unimportant, but that is not the case for thyroxine. In practical terms, patients should not assume that various brands or batches of thyroxine are the same or that 200 microgram tablets are four times as potent as 50 microgram tablets.

A recent joint position statement from The American Thyroid Association, The Endocrine Society and The American Association of Clinical Endocrinologists is a response to the current uncertainty (1). In summary, these groups recommend that patients should continue to use the same brand of thyroid medication throughout their treatment. *The report recommends strongly against change of brand without physician consultation.* It is now apparent that there may be pressure to change brands, for example from insurers who may reject payment for particular brand names, or may require a higher co-payment. If the brand is changed, the dose will need to be recalibrated by measuring serum TSH after two to three months. (The saving from changing to a less expensive medication may well be less than the cost of an extra serum TSH assay.)

The extent of batch-to-batch variation from the same manufacturer remains unknown, but it is accepted that there may be a loss of potency of up to 20% during the standard shelf-life of thyroxine tablets. Variation of this sort can be reliably detected only by measuring the serum TSH.

Storing Thyroxine

In Australia there has recently been the unique directive that patients should store bottles of thyroxine at refrigerator temperature, even when the bottles are no longer sealed. The inconvenience for the patient is obvious, but the effect of this arbitrary directive could be more

than merely inconvenient. It could be quite serious.

The need to keep thyroxine dry has been repeatedly emphasized (2) and one major US manufacturer directs as follows: "Store at 25C (15-30C) ... protect from light and *moisture*". Consider the condensation that will occur with daily opening of a refrigerated glass bottle, whatever it contains. There is obviously a high probability that the tablets will become damp. Loss of potency as the tablets become increasingly moist over several months would give the impression of under-treatment and lead

The report recommends strongly against change of brand without physician consultation.

to possible upward adjustment of dosage. After change is made to a fresh preparation, the adjusted dose could result in serious over-treatment. Clearly, the wisdom of this instruction should have been checked by the manufacturer, by measuring the thyroxine content of refrigerated tablets stored in a glass bottle opened daily over several months.

The European trend towards presenting thyroxine in bubble packs might go a long way towards alleviating some of the current uncertainty and confusion. If this method is shown to be beneficial, it would allow tablets to be kept in a dry dark environment, possibly with refrigeration.

Absorbing Thyroxine : Some Problems

The advice, generally given, is that thyroxine should be taken on an empty stomach, if possible separate from other medications. Thyroxine is sticky stuff – over 99.97% attaches to plasma proteins in the circulation so it is to be expected that it will also bind to food. The list of medications that can impair thyroxine absorption continues to increase. Iron and calcium preparations, antacids, cholestyramine and other exchange resins, sucralfate and soy products are documented to

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Thyroxine: Current Issues (continued from page 9)

have this effect. It is sound advice to separate thyroxine dosage by at least four hours from other medications to maximize absorption. If, however, the dosage schedule is stable with some other routine, it should not suddenly be changed.

Thyroxine in Pregnancy

Recent studies of serum TSH show that the replacement requirement for thyroxine increases by 25-30% within the first trimester of pregnancy. It is during this early phase of pregnancy that maternal thyroxine is especially critical for optimal fetal brain development. It is now recommended that the replacement dose of thyroxine should, where possible, be optimised before conception and adjusted to achieve serum TSH in the lower reference range, between 0.4 and 2.0 mU/l. There is a recent recommendation to increase the dose by about 25% as soon as pregnancy is confirmed.

Starting Thyroxine Therapy

It is often appropriate to begin thyroxine replacement at low dosage, for example only 25-50 micrograms daily, especially in the elderly, who may have coronary artery disease. Contrary to this practice, however, treatment can often begin with close to full replacement dosage at 100 micrograms daily. This dosage, for example, can be given to euthyroid patients after near-total thyroidectomy, or when suppressive therapy is resumed after temporary cessation of treatment for thyroid cancer follow-up, as well as in younger patients with newly diagnosed primary hypothyroidism. (It is a personal view that the instruction to *always* commence thyroxine at a low dose of 25-50 micrograms daily, as given in pharmacy manuals (2), is unnecessarily conservative.)

Adjusting the Dosage

Because thyroxine has a narrow therapeutic window, there are good reasons to aim for accurate replacement dosage. Adjustment is generally based on serum TSH, aiming for a target value in the range 0.5-2.0 mU/l, unless there are reasons to use a higher or lower dosage. If the thyroxine dose is changed, at least six weeks should elapse before reassessment. Arbitrary short-term dose alterations, based on day-to-day symptoms make no sense and can be very confusing.

Replacement and Suppressive Doses

It is important to distinguish between replacement and suppressive dosage of thyroxine. Standard replacement use of thyroxine is generally given to achieve a TSH target of 0.5-2mU/l. In some situations, however, the aim of treatment is to achieve subnormal levels of TSH below 0.2mU/l, to minimize TSH stimulation of thyroid tissue. This is often the aim in patients who have had differentiated thyroid cancer, and in the treatment of some euthyroid goitres. During suppressive therapy, the free T4 estimate is usually slightly above normal, but free T3 is usually not above the reference range, when corrected for age. The need for long-term suppressive dosage should be periodically reviewed to minimize possible adverse effects of excess thyroid hormone on bones and cardiac rhythm.

Uncertain Diagnosis

Sometimes the diagnosis of hypothyroidism has not been proven before replacement is started. While a person is taking a full replacement dose of thyroxine, there is no simple test that distinguishes between primary hypothyroidism and unnecessary treatment. If the initial documentation is not available, it usually does no harm to continue replacement, provided thyroxine is not being used to excess. Even a marginally elevated serum TSH value, or positive peroxidase antibody, indicates that the diagnosis of primary hypothyroidism is probably correct. Where a distinction must be made, a high serum TSH three weeks after cessation of treatment, or two months after reduction of dosage to only 50 micrograms daily, will confirm the diagnosis. It is helpful for patients with newly diagnosed hypothyroidism to be given documentation of their diagnosis, to avoid later doubt.

Thyroxine Treatment Alone?

The thyroid gland secretes two hormones, thyroxine (T4) and the more active triiodothyronine (T3) Most of the latter is formed, not in the thyroid, but by conversion from thyroxine in organs such as liver and kidney. This process also occurs when thyroxine is taken by mouth. The question of whether T3 is required in addition to thyroxine for

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TFI: 10th Annual Conference

Istanbul, Turkey

Conference Highlights

TFI held its 10th annual conference from September 16 – 18, 2004 in conjunction with ETA's 30th in Istanbul, Turkey. Unfortunately only a few member organizations could make the trip this year: seven countries and member organizations were represented (Canada, Denmark, Finland, France, Netherlands, Sweden, United Kingdom). Others sent greetings and reports.

ThyroWork

Here's a brief look at what TFI organizations have been doing in the past year and what they are planning ahead.

Canada: Thyroid Foundation of Canada

Founded in 1980, TFC is celebrating its 25th anniversary. It has about 3000 members coast to coast. Between 2003 and 2004, the structure of the organization has been totally changed, a very difficult and challenging process. We now have a board of eight members instead of thirty-nine. Our web site has been renewed. We have a new vision statement: "to provide leadership to eliminate thyroid disease". Our activities include: education on thyroid disorders for GPs, international thyroid update meetings, producing thirteen brochures on thyroid topics and a thyroid comic for teenagers.

A recent outreach project is described on page 7.



Denmark: Thyreoidea Landsforeningen

Founded in 1997, we now have 800 members. Many new projects are underway: cards to be displayed in waiting rooms, books with brochures for patients in endocrine departments, new information brochures, patient support groups, telephone helpline, web site and meetings as well as giving a research award of 7000 € for a project on T3/T4. We have good cooperation with doctors.



Finland: Suomen Kilpirauhasliitto ry



The Finnish patient organization, created in 1996, has about 4000 members and 16 regional associations belonging to the union. Our most important work is providing information: brochures, an Internet home page, a patients' magazine as well as information on radio, television and in newspapers. We also provide education and training for people active in the organization and carry on our rehabilitation camps. Our logo is the small flower Vuorenkili or Shield of the Mountain, the first flower to come out of the snow after winter. As it overcomes winter, we hope that thyroid patients will also overcome their thyroid problems.

France: Association des malades de la thyroïde

Thanks largely to our Association, some 427 complaints were filed against the government of France for failure to adequately protect its citizens against the radiation released from the Chernobyl cloud. We hope to meet with Ministry of Health officials later this year.



France: Forum "Vivre sans thyroïde"

Created in 2000, this Bulletin Board is the newest member of TFI joining in September 2004. It is not an association, but a bulletin board without fees; members just register on the web site. It has about 800 members, more than 190,000 hits and an average of 18 to 20 messages a day.



For an account of its activities, see pages 5-6.

The Netherlands: Schildklierstichting Nederland

The Dutch organization was founded in 1987 and has about 12,500 "donors". Our aims are: contact with patients (20 meetings a year, patient-to-patient telephone number, 10 groups, "thyroid phone"); we produce information (booklets, brochures, take part in health fairs and meetings); and, defend patients' interests (availability of T3, joining umbrella patients' organizations, developing new guidelines for thyroid cancer, as well as for hypo and hyper conditions).



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Sweden: Västsvenska Patientföreningen för Sköldkörtelsjuka (VPFS)

In Sweden, there are three organizations: Western Sweden (VPFS), Stockholm (SIS) and Northern Sweden (not in TFI). Only the VPFS attended the Istanbul meeting. It was founded in 1994 and has nearly 500 members. We run a web site, distribute the "NEJ" brochure to 500 health care centres and 2600 GPs. We also hand out the brochure to all newly diagnosed patients, organize lectures and meetings, publish information leaflets and articles in newspapers. We are also working on an education project for GPs. Our contacts with doctors and the ETA are very good.



United Kingdom: British Thyroid Foundation (BTF)



The BTF, created in 1991, has 8000 members, 16 local groups and 16 telephone helplines. We have been busy

appointing regional coordinators, starting a cancer group, revising and editing guidelines, leaflets and information pamphlets. We have held information and fundraising events and attended various professional meetings. We have established excellent cooperation with other patients' and physicians' organizations (TED, BTA) We give an annual thyroid research award of £ 10,000.

Down to Business

After hearing the reports from the member organizations and reading the greeting letters sent by those who could not attend the meeting, we got down to business and worked on the following topics: our financial report, membership fees and criteria. To encourage new organizations to join TFI, the annual fee is changing from \$50 US to \$50 Canadian as all accounts are now in Canada. A group applying for membership in TFI must be recommended by an organization such as ETA or ATA and will be considered "associate member on probation" for the first two years, without paying a membership fee.

We also discussed updates of the TFI leaflet and the TFI web site. All member organizations were asked to send a report three times a year (December, April, July) to keep in touch regarding our activities and projects. Also discussed were how to raise financial support for TFI.

With regret, we accepted Nancy Patterson's resignation as Secretary and from the Executive Committee for personal reasons. As we did not have a quorum, we could not elect a new board only fill in the vacant places of Secretary and Member-at-large. Future projects include establishing a list of goals and a five-year plan, as well as preparing a summary of the "milestones of TFI history".

TFI President, Yvonne Andersson, was invited to attend the annual meeting of the Society of Endocrinology and Metabolism of Turkey (SEMT), to give a presentation about TFI. The Society is very interested in participating in TFI. She was also interviewed by Turkish media.

During the ETA meeting, TFI had a small booth in the exhibition space. We had many contacts with interested doctors, particularly in Turkey, Greece, Serbia and Japan. We attended presentations on various subjects, among them new ranges for TSH, T3-T4 treatment and follow-up of thyroid cancer. The contacts with the organizers and the doctors were excellent. The Hilton Hotel provided us with excellent conditions, the people from Intratravel, responsible for the organization of the congress, were very friendly and efficient. We really enjoyed Turkish hospitality.

Turkish Delights

We also experienced this hospitality at the various social events: the ETA welcome reception, a cruise on the Bosphorus and dinner at the fish market. Some of us attended the gala dinner in the Hilton gardens. Regrettably, between the

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Cappadocia: a hillside village.

ATA Comes to Canada



The American Thyroid Association held its 2004 meeting in Vancouver, British Columbia from September 28 to October 3. Known for its generous rainfall and inclement weather, Vancouver nonetheless rose to the occasion and provided visitors with warm, dry, sunny days and comfortable evenings for the entire conference.

TFI was represented at this meeting by President Yvonne Andersson who participated in a full agenda. Also attending were Nancy Patterson, NGDA, Dr. Larry Wood, TFA, and Ted Hawkins, TFC.

On the evening before the conference, a patient information session was held, chaired by Dr. Wood, with Dr. G.E. Wilkins of Vancouver and patients participating. It focused on some of the complex and difficult issues confronting thyroid patients on the road to stability. To an audience of over 100 members of the public plus conference participants, the cases presented were indeed pertinent and stimulated enthusiastic discussion. The involvement of all and the number and quality of questions readily demonstrated that the thirst for thyroid information is far from quenched.

The conference enjoyed a strong registration of members from all over the world. Intricate research details were shared, discussed and controversies aired. The combination therapy of T3 and T4

continues to generate interest although studies have failed to demonstrate any significant benefit to patients. If there is a secret formula for combining these two hormones, it is still well hidden. Recombinant TSH experience is being gained more widely. This is initiating the search for additional applications in patient-friendly regimens.

Another controversial topic in thyroid hormone therapy is the interchangeability of medications, determining their equivalence and the implications for patients. Professor Jim R. Stockigt of Melbourne, Australia ably presented this topic, citing "Significant issues of variable potency and stability of LT4 that remain unresolved."

Paul Ladenson led discussions to explore ways of developing the "Alliance" into a vehicle that would meet the needs of all thyroid patient-oriented, organizations around the world. The need was recognized for these groups to work with professional associations at all levels - national, regional and international. TFI enjoys a strong bond with both ETA and ATA. Time is helping to develop liaisons with the Latin American and Asian associations as well. It is hoped that TFI's presence in Buenos Aires will afford opportunities to achieve new levels of cooperation. ♣

Professor Stockigt's presentation is featured on page 8.

TFI: 10th Annual Conference (continued from page 12)

different lectures and meetings, there was not much time to visit the beautiful city of Istanbul. We managed, however, to rush through the "Grand Bazaar" for some shopping, to taste some really wonderful



The beauty of the Blue Mosque.

Turkish food in various small restaurants and to have a look at the Blue Mosque and the Topkapi Palace. After all this rushing about, what better way to relax than to try out the famous Turkish baths and massage – which some of us were brave enough to do. We truly enjoyed the atmosphere of this very special city with its unique mixture of modern European and ancient oriental culture. ♣



Weaving: An ancient craft.

Northern Lights



In January 2005, a new Nordic organization serving the interests of thyroid patients was established in Oslo. Its purpose is to strengthen cooperation between thyroid patient organizations in all Nordic countries and to share resources and information. The most important issue will be to increase the knowledge of thyroid diseases in the general public and among doctors and other health workers.

The name of the new organization is *Nordisk Thyreoidea Samarbeid*. Five organizations from three countries Norway, Sweden and Finland attended the meeting in Oslo. TFI President Yvonne Andersson from Sweden was also present.

Martha Flermoen, Chairman of the Norwegian organization, was elected as President with Paavo Koistinen, Chairman of the Finnish organization, as Vice-President.

Most hypo thyroid patients have a low metabolism. The disease is common, but for many patients it can take years before they get the right diagnosis, with very negative consequences for their health. Common symptoms are weight gain, tiredness, being cold, depression and lapse of memory.

The thyroid gland is shaped like a butterfly. The emblem of the new organization therefore consists of five butterflies,

one for each of the Nordic countries. The three attending countries, Norway, Sweden and Finland, hope that Denmark and Iceland will soon join the new Nordic Thyroid organization and claim their butterflies. 🦋



A Founding Member Ulla Slama, Vice-President Paavo Koistina and President Martha Flermoen.

AACE/ATA/TEX Joint Statement

RE: FDA approval of generic levothyroxine preparations as equivalent to branded preparations

The American Association of Clinical Endocrinologists (AACE), representing over 4,800 clinical endocrinologists, The American Thyroid Associations (ATA), and The Endocrine Society (TES) have stated that as levothyroxine is a drug recognized to have a narrow toxic-to-therapeutic ratio with significant clinical consequences of excessive or inadequate treatment, it should not be interchanged. Some of the potential adverse events include: recurrence of symptoms, osteoporosis, atrial fibrillation, worsening of ischemic heart disease, preterm delivery in pregnancy, and hypercholesterolemia. There are 12 tablet strengths of levothyroxine available that vary by as little as 9% in drug content, reflecting the close titration that is required for optimal patient management. Thirteen million Americans are on levothyroxine products and those especially susceptible to incorrect titration include the elderly, pregnant women and their developing fetuses, and those with thyroid cancer.

What should physicians caring for patients on levothyroxine therapy do?

1. Encourage your patients to ask to remain on their current levothyroxine preparation, until they consult with you directly.
2. Make sure your patients understand that if they receive a new levothyroxine preparation, they will need to be retested with a serum TSH to determine if they need dose retitration.

Levothyroxine brands are not interchangeable. The American Association of Clinical Endocrinologists (AACE) recommends that patients use the same brand consistently, throughout treatment.

Thyroxine: Current Issues

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optimal replacement has been contentious. Three recent double-blind cross-over studies showed no benefit from using T3 in addition to thyroxine, in terms of symptom relief, cognitive function, quality of life, or satisfaction with treatment.

In standard replacement therapy, it may not be sufficient to merely reduce serum TSH into the standard reference range of about 0.4 - 4.0 mU/l. Serum TSH is logarithmically distributed and most individuals appear to have a set-point in the range 0.5-2.0 mU/l. Unless there is some complicating factor, thyroxine dosage should be adjusted to achieve TSH values in this range. Periodic monitoring of serum TSH every 6-12 months is appropriate, to document individual response and to adjust for variations in the potency of synthetic thyroxine preparations. Such assessments will remain the cornerstone of the doctor - patient relationship to ensure the best therapy. 🍷

1. American Association of Clinical Endocrinologists, The Endocrine Society and American Thyroid Association. Joint statement on the use and interchangeability of thyroxine products January 2005. www.thyroid.org/professionals/advocacy/04_12_08_thyroxine.html

2. US Pharmacopeia drug information.

www.nlm.nih.gov/medlineplus/druginfo/uspdi/202566.html
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Future International Thyroid Conferences

2006 Naples, Italy

2007 Leipzig, Germany

ThyroWorld

Deadline for the next issue: January 1, 2006

For logos, photos and other artwork, please send **originals**. Other copy may be sent electronically.

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13th International Thyroid Congress

Buenos Aires, Argentina

October 30 – November 4, 2005

Dear Colleagues:

We are very happy to invite you to the 13th International Thyroid Congress (ITC) that will be held in Buenos Aires, Argentina, in the year 2005.



This is a joint meeting of the four sister societies: ATA, AOTA, ETA & LATS. According to the traditional "rule of rotations", the International Coordinating Committee (ICC) has designated Buenos Aires as the host city for the next ITC. As usual, the scientific program will cover the most up-to-date issues in thyroidology. The Program Organizing Committee (POC) is composed by three relevant members of each sister society, while the Local Organizing Committee (LOC) is in charge of the congress organization.

On behalf of the LOC members, it is my great pleasure to extend an invitation to all the colleagues around the world who are interested in thyroid field. We wish to make the 13th ITC a memorable event in terms of science, social activities and personal friendship.

Buenos Aires, the capital city of Argentina, is located at the occidental shore of the Rio de la Plata. Just a century ago, in such a place, the tango was born. This worldwide famous music will accompany you in the best moments of the social program, as well as the charm and the glamour of Buenos Aires, which is one of the most beautiful and cosmopolitan cities of the world.

Buenos Aires has a wide variety of comfortable hotels, with convenient prices to fit the economy of each individual person. The excellent food, specially meat, is one of the most outstanding qualities of Argentina, and usually becomes as the great pleasure of gourmand tourists. As you can see, Buenos Aires should capture you in a real sense. For this reason, you are very welcome to share with us the surely exciting 13th ITC, which is hosted by the Latin American Thyroid Society (LATS). 🍷

Hugo Niepomniszcz, MD PhD
Chairman of the LOC, 13th ITC

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