Thyroid Foundation of Canada

thyrobulletin

La Fondation canadienne de la Thyroïde

Volume 24, No. 2 **Summer 2003**

Graves' hyperthyroidism
(thyrotoxicosis)

Graves' disease is named after the Irish physician who described several cases in the London Medical Journal in 1835. It was actually first described by Parry a few years earlier. In Europe, the disease is Basedow's disease. In all countries it is also known as thyrotoxicosis. Graves' disease, by far the most common cause of hyperthyroidism in Canada, affects perhaps one in every 100 people. It appears to be becoming even more common. The disease is an inherited disorder, although not every member of the afflicted families will suffer this condition. It is more common in females than in males.

Thyroid stimulating antibody

Graves' disease is an autoimmune disorder. It is caused by an abnormal protein, called thyroid stimulating antibody. This antibody stimulates the thyroid gland to produce large amounts of thyroid hormone in an uncontrolled manner. In normal people, the production of thyroid stimulating antibody (and other abnormal antibodies) is prevented by a surveillance system. This condition consists of certain blood cells called suppressor and helper lymphocytes and Killer (K) cells, as well as other constituents. The suppressor lymphocytes suppress unwanted lymphocytes.

Measurement of the thyroid stimulating antibody present in the blood of most patients with Graves' disease is not usually necessary in order to establish the diagnosis.

Clinical features

The symptoms and signs of Graves' hyperthyroidism are due to the effects of excess amounts of thyroid hormone on body function and metabolism. Common symptoms include weight loss, nervousness, irritability, intolerance to hot weather, excessive sweating, shakiness, and muscle weakness. Other signs include a rapid pulse, loss of body fat and muscle bulk, thyroid enlargement (goitre), fine tremors of fingers and hot, moist, velvety skin.

About 50% of patients also have significant eye signs (ophthalmopathy). The eyes, which bulge from their sockets are red and watery and the lids are swollen. Quite often the eyes do not move normally because the swollen eye muscles are unable to work precisely. The remaining 50% of patients with Graves' hyperthyroidism may have slightly bulging eyes because of spasm of the muscle of the lids, giving them a staring appearance.

Thyroid hormones have a wide variety of effects on the body and the symptoms and signs reflect these. In simple terms, all the metabolic processes are speeded up; for example, the pulse rate is rapid (over 100) bowel function is increased (diarrhea), and the sweat glands work excessively. The nervous system is also stimulated so the patient becomes irritable and nervous. Despite increased appetite, the patient usually loses weight because food intake cannot keep up with the increased breakdown of body proteins. The end result is a thin, hot, nervous patient with 'poppy' eyes and a goitre – a classical clinical situation quickly recognized by any medical practitioner who has previously seen such a patient.

Treatment

Because Graves' hyperthyroidism is caused by a genetically determined abnormality of the immune system, the problem is complex and there is at present no specific treatment for the underlying abnormality. Since the end result of this problem is an overstimulation of thyroid function, treatment of the symptoms is quite easy – one can either surgically re-

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move part of the thyroid (thyroidectomy), destroy the cells with radioactive iodine, or block thyroid hormone production with antithyroid drugs.

Radioactive iodine

Although radioactive iodine is by far the simplest and most convenient treatment, its use in younger adults and children has previously been of some concern because of the possible harmful effects of radiation. Radioactive iodine has been used for over 50 years and there is no good evidence of any harmful effects. Most thyroid specialists would recommend its use in all patients with Graves' disease over the age of 20-25, some would use it in children as well. However, it occasionally aggravates the eye signs.

Radioactive iodine is usually given in the form of a capsule. The dose is calculated from the size of the goitre by performing a Thyroid Uptake Test. Because radioactive iodine takes several weeks to take its full effect, antithyroid tablets are also sometimes given until such time as the full effect occurs. More often than not, patients end up hypothyroid due to the radioactive iodine and have to take thyroxine for life.

Antithyroid drugs

Antithyroid drugs (of which propylthiouracil and methimazole are the only ones available in Canada) are almost mandatory in children and adults under the age of 20-25. They may also be used at any age so as to bring about remissions, or prior to ablation therapy. There are two main drawbacks with this type of treatment:

1) patients must take tablets for many months or years;
2) once treatment has stopped there is only about a 50% chance that the disease will not flare up again.

In addition, a very small percentage suffer side effects which can be severe. Eventually, most patients require treatment with radioactive iodine or thyroidectomy. Another tablet that can be given to treat the symptoms of hyperthyroidism is propranolol. This drug blocks the effects of excess thyroid hormones on the heart, blood vessels, and nervous system, but has no direct effect on the thyroid gland.

Thyroidectomy

Surgery is sometimes recommended for the 80% of patients under the age of 20 who have a recurrence of hyperthyroidism after antithyroid drugs. Thyroidectomy is also recommended for patients of any age in which the goitre is so big that it causes blockage of the windpipe (trachea) or food passage (esophagus). In England and Europe, thyroidectomy is performed for Graves' disease much more often than in Canada because of experience and tradition. Thyroidectomy requires admission to hospital for about 5 days and removal (by an experienced surgeon) of all but a small portion of the gland.

After treatment with radioactive iodine or thyroidectomy, it is hoped that enough of the thyroid gland remains to function normally. Occasionally the gland becomes overactive again since the abnormal stimulating antibody is still being produced by the lymphocytes. In other patients, there is a strong tendency for the remaining thyroid gland to become underactive (hypothyroidism) – perhaps 80% of all patients with Graves' disease will eventually require lifelong thyroid hormone replacement therapy. This is not considered a problem as long as the hypothyroidism is recognized and treated. It is much more of a problem for a patient to have a recurrence of hyperthyroidism because of failure to remove enough gland or if too small a dose of radioactive iodine is given. Indeed, some specialists deliberately destroy the thyroid in order to prevent a recurrence of hyperthyroidism, and immediately treat with thyroid hormone in anticipation of hypothyroidism.

Other causes of hyperthyroidism

In Canada, Graves' disease accounts for at least 90% of all patients with hyperthyroidism. Hyperthyroidism can also occur in older patients with longstanding nodular goitres.

Other uncommon causes of hyperthyroidism in Canada are painful (subacute) thyroiditis caused by a viral infection of the thyroid gland in which the hyperthyroidism is due to a leakage of thyroid hormone from the swollen, damaged gland, and silent thyroiditis, a similar condition but without the painful swelling of the thyroid. Multinodular or single nodular goitres may become autonomous and produce hyperthyroidism. A few other rare causes of hyperthyroidism need not be discussed here.

The foregoing information appears in the Foundation's Health Guide # 6. For the complete list of Health Guides available from the national office or your local chapter, please see below.

Health guides on thyroid disease

The following Health Guides on Thyroid Disease are available in English and French.

The information in these Health Guides was provided by Drs. Jody Ginsberg, Ian R. Hart, Irving B. Rosen, Sonia R. Salisbury, Robert Volpé, Paul G. Walfish and Jack R. Wall. The medical information in these brochures is for general patient education. For individual treatment or diagnosis consult your personal physician.

1. *The Thyroid Gland: A General Introduction*
2. *To Confirm the Clinical Diagnosis*
3. *Hypothyroidism*
4. *Thyroid Nodules*
5. *Thyroiditis*
6. *Graves' Hyperthyroidism (Thyrotoxicosis)*
7. *Graves' Eye Disease (Ophthalmopathy)*
8. *Thyroid Disease, Pregnancy and Fertility*
9. *Thyroid Disease in Childhood*
10. *Thyroid Disease in Late Life*
11. *Surgical Treatment of Thyroid Disease*
12. *Thyroid Cancer*
13. *Common Concerns of Thyroid Patients*

All Health Guides are available through the Foundation's national office or from your local chapter (see back page). Please send a self-addressed business size envelope stamped with two 48 cents stamps.

Tous les Dépliants Santé sur les affections thyroïdiennes sont disponibles auprès du bureau national de la Fondation ou de votre section locale. Veuillez nous faire parvenir une enveloppe d'affaires adressée à soi et affranchie de deux timbres de 48 cents.

Graves' eye disease
ophthalmopathy

Graves' eye disease is an eye condition which occurs in about 50% of patients who currently have, or have had, Graves' hyperthyroidism. However, approximately 10% of patients who have this eye disease never develop hyperthyroidism. The reasons for the association of hyperthyroidism with the eye disease are not completely understood.

Graves' eye disease, like Graves' hyperthyroidism and Hashimoto's thyroiditis, is an autoimmune disorder. It is caused by the reaction of antibodies and certain white blood cells called lymphocytes, with proteins in eye muscle and the connective tissue and fat around the eyeball. This condition must be distinguished from the mild eye signs of 'poppy' eyes and spasm of the eye lids which occur in most hyperthyroid patients due to an effect of excessive thyroid hormones.

Clinical features

The characteristic features of Graves' eye disease are symptoms of inflammation of the eye tissues. The eyes are painful, red and watery – particularly in sunshine or wind. The covering of the eye is inflamed and swollen.

The lids and tissues around the eyes are swollen with fluid. The eyeballs bulge out of their sockets. Because of eye muscle movement, the eyes are unable to move normally and there may be blurred or double vision.

On examination, it can be seen that the eyes are pushed out of their sockets. This can be measured using an instrument called an exophthalomometer.

Laboratory tests

There are no tests currently available to confirm the diagnosis of Graves' eye disease although good progress is being made in Canada in the development of a simple antibody test to measure the proteins in the blood which cause the eye disease. Such a test would be useful in patients with Graves' hyperthyroidism to identify those who may be likely to develop the eye disease.

Natural history

The eye changes tend to 'burn out' within a period of about 24 months and, in most cases, there is a satisfactory end result even without any treatment. The double vision and the bulginess usually do not disappear completely. Many patients are worried by the cosmetic appearance of their swollen, bulgy eyes, whereas others, with less severe defects, are inconvenienced by their inability to read clearly because of double vision. The impact of the eye disease also depends on the age, sex, and occupation of the patient.

Treatment

Unfortunately, there is no satisfactory treatment. Because hyperthyroidism seems to influence the eye disease, it is very important to treat the hyperthyroidism quickly and effectively but to avoid hypothyroidism, which also harms the eyes. In most patients, the eyes tend to get somewhat better when the thyroid abnormality has been treated.

In a few patients, the condition progresses regardless of what is done to the thyroid gland. These patients must be treated with strong drugs such as steroids or immunosuppressive drugs to prevent the unlikely occurrence of optic nerve swelling and blindness. If these measures do not work within a few days, it may be necessary to relieve pressure in the orbit by removing part of the tissue either by operation or by treating the eyes with X-rays. Both treatments very quickly reduce the pressure on the eyeball and the surrounding orbital tissues and prevent permanent optic nerve damage or glaucoma.

Long term management

Once treated, or when the eyes have 'burnt out' without treatment, the eye inflammation rarely recurs and treatment need not be continued. Patients who have not had thyroid disease previously must be examined on a regular basis in case they develop thyroid disease. Patients with eye disease who have had their hyperthyroidism treated previously should also be examined at regular intervals to make certain that thyroid function remains normal since recurrence of hyperthyroidism, or development of hypothyroidism, may cause the eye disease to flare up.

The foregoing information appears in the Foundation's Health Guide # 7. For the complete list of Health Guides available from the national office or your local chapter, please see page 2.

Hyperthyroidism: Just the Facts

- Hyperthyroidism occurs when the thyroid gland is overactive and produces too much thyroid hormone.
- Hyperthyroidism affects approximately 2% of women and 0.2% of men.
- Graves' disease, an autoimmune disorder, is the most common cause of hyperthyroidism.
- The signs and symptoms of hyperthyroidism are:
  - irritability
  - rapid heart rate
  - sleeplessness
  - weight loss in spite of increased appetite
  - heat intolerance
  - eye changes
  - diarrhea
  - neck swelling/goitre
- Hyperthyroidism can speed up the body's metabolism by 60 - 100%.
- There are three main treatments for hyperthyroidism – anti-thyroid drugs, radioiodine therapy and surgery. All are effective, though no treatment ever results in a complete cure.
- Increasingly, radioiodine is becoming the first-line therapy for hyperthyroidism caused by Graves' disease.
- After treatment for hyperthyroidism some patients become hypothyroid and will need to take levothyroxine for life.
- ***Thyroid storm*** – severe clinical hyperthyroidism – is a medical emergency. Its symptoms include tachycardia and fever.

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Important Notice:

The information in *thyrobulletin* is for educational purposes only. It should not be relied upon for personal diagnosis, treatment, or any other medical purpose. For questions about individual treatment consult your personal physician.

Avis Important:

Les renseignements contenus dans le ***thyrobulletin*** sont pour fins éducationelles seulement. On ne doit pas s'y fier pour des diagnostics personnels, traitements ou tout autre raison médicale. Pour questions touchant les traitements individuels, veuillez consulter votre médecin.

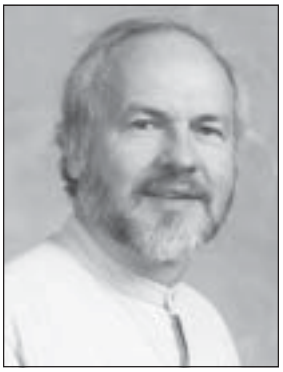
President's message

Who Moved My Cheese?, a gem of a book by Spencer Johnson, deals with change in our work and lives. The story is about two mice and two little people all of whom live on cheese as their main source of food. But the impact of the story is how they react when their cheese gets moved.

This year has seen some changes in the Thyroid Foundation of Canada and we are discussing others. Our Annual General Meeting was postponed from June to October because of the SARS crisis. We are building a financial plan which will mean we raise money actively at a national level. We will embark on an examination of our governance structure.

Johnson's message is that they keep moving the cheese, i.e. change happens. Part of our job is to anticipate that change and to be ready for the cheese to move. We need to monitor change. His analogy is we need to smell the cheese often so that we know when it is getting old.

We need to adapt quickly to change. The quicker you let go of the old cheese the sooner you can enjoy the new cheese. He suggests we enjoy change, that we savour the adventure and enjoy the taste of new cheese.



Ed Antosz
National president/Président national

I mention this at the present time because change is not easy. People seldom want to change as they are comfortable with how they are doing things. We know what we are doing and how to go about completing our current tasks. We don't always want new tasks and often resist doing them differently. However, change is an interesting challenge and welcomed by many.

Johnson tells us that we need to be ready to change quickly and enjoy it again and again – because they keep moving the cheese!

I also mention the notion of change because you will find in the *Foundation's mailbox* a letter from H. Strachan, a member of the Foundation, with a reply from Dr. Volpé and me. Ms. Strachan is unhappy with the fact that we accept sponsorship of *thyrobulletin* from several pharmaceutical companies.

In an ongoing effort to cover all aspects of a malfunctioning thyroid gland, this issue concentrates on Graves' hyperthyroidism. Our goal is to bring you as much information as possible on all aspects of thyroid disease. Your membership and support will help the Foundation to reach its goals and to continue programs for the benefit of all those concerned about problems related to thyroid disorders.

Message du président

Who Moved My Cheese?, un très bon livre par Spencer Johnson, traite du changement dans notre travail et notre vie. Il raconte l'histoire de deux souris et de deux petites personnes pour qui le fromage est leur principale source de manger. Mais l'impact de l'histoire est comment ils réagissent lorsque leur fromage est déplacé.

Cette année a vu des changements dans La Fondation canadienne de la Thyroïde et nous en discutons d'autres. Notre assemblée générale annuelle fut remise du mois de juin au mois d'octobre à cause de la crise SARS. Nous construisons un plan financier, ce qui veut dire que nous ramasserons activement des fonds au niveau national. Nous examinerons notre structure de gouvernance.

Le message que Johnson nous fait voir est qu'on n'arrête pas de déplacer le fromage. Une part de notre travail est de prévoir ce changement et d'être prêt pour le déplacement du fromage. Nous devons suivre le changement de proche. Son analogie est que nous devons souvent sentir le fromage afin de savoir quand il vieillit.

Nous devons nous adapter vitement au changement. Le plus vite le vieux fromage est parti le plus tôt le nouveau fromage peut faire plaisir. Il suggère de prendre plaisir dans le changement, de savourer l'aventure et prendre plaisir du goût du nouveau fromage.

Je mentionne ceci en ce temps parce que le changement n'est pas facile. Le monde veut rarement faire changement car nous sommes confortable avec la méthode courante de faire les choses. Nous savons ce que nous faisons et comment faire pour compléter nos tâches courantes. Nous ne voulons pas toujours des tâches nouvelles et souvent nous résistons de les faire différemment. Cependant, le changement est un défi intéressant et bienvenu par beaucoup. Johnson nous dit que nous devons être prêts de changer vitement et d'y prendre plaisir de plus en plus souvent – parce qu'on n'arrête pas de déplacer le fromage!

Je mentionne aussi l'idée du changement parce que vous trouverez dans *Foundation's mailbox*, une lettre de H. Strachan, un membre de la Fondation ainsi qu'une réponse par le Dr Volpé et moi-même. Ms Strachan n'est pas heureuse du fait que nous acceptons le parrainage de quelques compagnies pharmaceutiques pour le *thyrobulletin*.

Dans un effort de couvrir tous les aspects d'un gland thyroïdien mal fonctionnant, ce numéro se concentre sur l'hyperthyroïdie Graves. Notre but est de vous apporter autant de renseignement possible sur tous les aspects des affections thyroidiennes. Votre adhésion et appui aideront à la Fondation d'atteindre ses buts et de continuer les programmes pour le bénéfice de tous ceux et celles qui ont des problèmes par rapport aux affections thyroidiennes.

Letters to the doctor

Robert Volpé, OC, MD, FRCPC, MACP, Medical Adviser to the Foundation

As a new member of the Foundation I was reluctant to write about my problem, but as I started receiving *thyrobulletin* and I found out I am not alone, I took courage. I am a 43 year old woman and I was diagnosed with hyperthyroid Hashimoto's four years ago. I have six nodules with one measuring 14 mm. My latest TSH test is at 400 and I am taking 75 mg of levothyroxine. My questions are:

1. Can a Hashimoto's thyroiditis be hyperthyroid?
2. Even though I am taking medication I rarely feel good. I always have symptoms of hyperthyroidism. Is this going to be my way of life?
3. Can a surgery help me?

Rounda Faitel
Rambouillet, France

1. *A patient with Hashimoto's thyroiditis can certainly be hyperthyroid. There are two types of hyperthyroidism, which occur with Hashimoto's thyroiditis: the first is a combination of Graves' Disease and Hashimoto's thyroiditis (sometimes referred to as Hashitoxicosis) in which both conditions are equally present and the Graves' disease would be more evident under that circumstance. The second would be a form of inflammation of the thyroid, which can occur with Hashimoto's thyroiditis, in which there is a transient increased output of thyroid hormone, but not increased synthesis of thyroid hormone. This can only last several weeks at best.*
2. *Generally speaking, patients who had a period of hyperthyroidism and after are put on thyroxine feel perfectly well if their levels of thyroid hormone and TSH values are in the normal range. However, there are some people who do not feel normal despite normal values for all of these parameters. In the latter situation, the lack of well* being *cannot be attributed to the thyroid status, but may be due to other factors.*
3. *Surgery will not help you under these circumstances.*

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On www.thyroid.ca, in Frequently Asked Questions #4, you indicate that the total serum T3 test is the "best measure of the appropriateness of the dosage" for patients who are taking thyroxine by mouth. However, in British Columbia, this test is not paid for by the medical plan unless there is a diagnosis of hyperthyroidism. The TSH is the routine test for hypothyroid patients on thyroxine. If that is abnormal, then the T4 is normally done next. I moved over a year ago, and thus changed doctors. The new doctor ordered a TSH for me, which was .033 (in April 2002), apparently indicating too much thyroxine. My free T4 was in the high range of normal (normal being indicated as 10.5 to 20.0), but I do not have the exact result. Another T4 test result was 133, with the maximum normal being 140 (not sure exact name of this test). I was on 150 mcg of Synthroid before these tests, and the doctor reduced the dosage to 125 mcg. She also sent me for a bone density test, which indicated that I have mild osteopenia. She indicated that excess thyroxine can cause osteoporosis. In January of 2003 my free T4 was 18.1, again high normal. The doctor reduced my dosage to 112 mcg. Keep in mind that I also started on hormone replacement therapy around April 2002, as I was post menopausal. Not sure how this affects the thyroid. I am on a patch which combines estrogen and progesterone, and I am told it is a fairly low dosage. The patch indicates it should be changed twice per week, but I change it only once a week. In April 2003 my free T4 was 19.3, even higher. However, before I got the result of this test I was feeling that if anything, my dosage of thyroxine was too low, due to being cold, slightly constipated, tired, fuzzy-headed, and also having my eyes quite sensitive to the sun again. I don't know if the eye sensitivity is related, but when it came back I recalled that it used to be a major problem for me prior to starting thyroxine. At that time, if I didn't wear sunglasses my eyes would be streaming. It hasn't gotten back to that stage yet, thankfully. My doctor wanted to reduce my dosage again, but I requested a total T3 test, explaining to her about the information on the thyroid web site. She requested the test, but the lab would not do it because she had not indicated a diagnosis of hyperthyroidism. When we determined why the lab did not do the test, she added a diagnosis of "iatrogenic hyperthyroidism", and the lab then performed the test. My total T3 result was 1.10, with an indicated normal range of 0.70 to 2.10. On this basis, the dosage of 112 mcg was continued. I see on the thyroid web site that you indicate the range of normal for the total T3 is 1.2 to 3.4. Does this mean my dosage is actually too low? To summarize, I have several concerns:

1. If the total T3 is the most appropriate measure of the dosage for a person on thyroxine, one would think that this would be the first test done instead of the 2nd or 3rd, to save costs on lab tests. Is the total T3 a more expensive test to do? If not, why would a provincial health plan not allow it as the first diagnostic test?
2. The free T4 and the total T3 seem to give conflicting results. Why is this?
3. The range of normal at my lab differs from your indicated range of normal. Why is this, and should I be comparing my result to your range of normal, or theirs?
4. Does an excess dosage of thyroxine cause osteoporosis? Frequently Asked Questions #7 indicates this is not true. If so, why do doctors think it is true?
5. Can you tell me where to find more information on the studies that have been done?
6. One last question – can the dryness or wetness of the mouth be related to the excess or lack of thyroxine?

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HEAD&NECK CANCER FOUNDATION

Thyroid Foundation of Canada gratefully acknowledges the support of the Head & Neck Cancer Foundation in sponsoring *Letters to the doctor.*

Letters to the Doctor . . . continued from page 6

My brother is also on thyroxine. He indicates that his mouth is always fairly dry. I am the opposite, and feel that my mouth is too wet. When I first started on thyroxine, my mouth was extremely dry as my body adapted to the thyroxine. The pharmacist explained that this would go away, and it certainly did, quite quickly. Thank you very much for any information you can provide.

Dorothy Kelt
Nanaimo, BC

To respond to your various questions, I would say the following: The total T3 is actually a more expensive test than the T4, and thus has not been utilized by most provinces and is not generally recognized as a very useful test, although it really is very useful. Because of its added expense, it will likely not become the first test done. Moreover, the TSH test is very sensitive, and will continue to be the first test performed. Most physicians who do get the T3 test prefer to do the free T3 at present, and this is what I do as well. The range for the free T3 is 2.6 to 5.7 pmol/l. It is quite true that the free T4 and free T3 may at times give conflicting results. For example, the free T4 may drop to very low levels, while the free T3 remains normal or sometimes even high. This is because the control of these two thyroid hormones may differ slightly and give such results.

An excessive dosage of Thyroxine may be one of the causes of osteoporosis. However, generally speaking, there has to be quite a severe elevation of thyroid hormone levels, which is necessary to bring about osteoporosis. You may look up in a major textbook on the thyroid, which is entitled 'Werner's and Ingbar's The Thyroid' which will provide information regarding the studies that have been done.

As for the wetness or dryness of the mouth, if the dosage of Thyroxine is not excessive, there should be no effect on the wetness or dryness of the mouth.

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On page 11 of the Spring 2003 issue of *thyrobulletin* in the *Letters to the doctor* column, there is a statement about herbal medicine "*It is when you are not on any thyroid medication that such agents can be potentially harmful. The way you are taking them is quite acceptable*".

So, if you are on thyroid medication is it then acceptable to eat kelp, carrageenan and seaweed if they are in foods such as sushi etc.(but not a pill supplement)? I fear eating sushi because of these ingredients.

Isabelle Leibovitch
Toronto, ON

Iodine works on the thyroid gland to change its metabolism. If the thyroid gland is not working, due to the ingestion of Thyroxine, then it does not matter whether a person takes iodine or not. Thus, if they are on Thyroxine they can eat Sushi.

*****

First of all, let me thank you for the *thyrobulletin*. It is absolutely wonderful! There is always something of interest, well-prepared and informative. I also have a medical question. This past November, I did the Thyrogen-challenge and body scan. It was a huge improvement over the hypothyroid state. And the radiologist thought the results were as good as those from the old-fashioned way. As part of the process, my blood was also analyzed for thyroglobulin. Last week at my quarterly endocrinology check-up, I found out that my routine blood test from a month ago showed undetectable thyroglobulin levels. However, the blood test as part of the challenge in November showed 6 ng/ml thyroglobulin. My endocrinologist was not sure how to interpret this, with the procedure being so new. How would you interpret this? Should I be concerned?

Louise Beggs
Stittsville

As for the serum thyroglobulin of 6 ng/ml, actually that is very good and you do not need to be concerned about this.

Chapter news

Avalon/St. John's

The June 17th display at our local teaching hospital, the Health Sciences Centre, was a success as a result of the great work of all the chapter's executive and members. The display ran from 10:00 am to 4:30 pm. There was hardly a moment when we didn't have someone inquiring at the display; they ranged from patients to visitors, hospital employees, and doctors including endocrinologists. Most of the literature we had available for the public disappeared.

Avalon chapter volunteers at the June 17th display

From left to right, Kathryn Downton, president and Grace Bavington, secretary.

Andrew Blundon, treasurer.

Burlington/Hamilton

We are selling **entertainment coupon books** again this year. They save you money, make great gifts and will be available from the chapter, September 1, 2003**.** Order early before they are sold out. To order, or to sell books, call Tammy: (905) 577-2433, 1-866-377-4447 (toll free) or (905) 381-0475. **Save A Tape** project. Please save your tapes from some A&P, Dominion and Ultra Food Mart stores in our area. Contact Tammy for more information. Bring your tapes to the meetings or mail them to the chapter office.

Thank you to everyone who took part in our spring events including the May 3, Annual Mayor's Walk – special thanks to Dan Butt of Kvaerner Constructors and Wendy McInnes of Levis. Over 85 people attended the education meeting and AGM in Stoney Creek.

3rd Annual Flower Sale
Left to right is volunteer member Cecila Burt of Hamilton, Tammy Butt, Chapter President of Ancaster and Darlene Leblanc, Chapter Vice President of Caledonia.

The 3rd Annual Flower Sale was a great success, sold out both days. Support from our members was fantastic.

In Brantford 55 people attended the meeting to hear about natural thyroid hormone replacement. Seven people volunteered to help the chapter in future events. Volunteer planning sessions are being planned for Brantford, Hamilton and Burlington in the coming months. Please plan to attend.

Kingston

The chapter board warmly thanks the Kingston chapter members who responded so promptly and generously to the chapter's first direct mail fundraising venture. The money raised will be allocated to the Diana Abramsky Research Fund and chapter activities, as specified by the donors.

We are pleased to announce that Rick Choma, Editor of *thyrobulletin*, has volunteered to be the chapter's Publicity & Fundraising Chair.

On June 17, we held an education meeting, *Thyroid cancer management breakthrough, forum for thyroid cancer survivors*. Dr. Robyn Houlden, FRCPC, Associate Professor, Division of Endocrinology, Queen's University, gave a comprehensive review of thyroid cancer. She was joined by Kim McNally, thyroid cancer survivor and Eric Piurko, Pharmacist, Wal-Mart. Kim spoke of her experiences with thyroid cancer and Eric Piurko presented information about the Trillium Drug Program**.** The meeting was sponsored by Theramed Corporation.

Thanks to the Ladies Auxiliary, Army, Navy and Air Force Association, Kingston for their generous donation of $1,000 for the work of the chapter.

On June 9, Margaret Burdsall, chapter president, and her husband Bernard marked their 60th wedding anniversary. An open house celebration with many family and friends was held Saturday, June 28, 2003.

Picture by, Kyle Hoobin, The Kingston Whig-Standard.

Bernard and Margaret Burdsall at their 60th wedding anniversary celebration.

London

The London area chapter held its 3rd annual "Touch of Spring" Fashion Show on April 10, 2003 at the Hellenic Community Centre in London. The goal of selling 300 tickets was reached. After the dinner, Dr. Terri Paul "kicked off" the evening with a brief introduction on thyroid disease. Again, the models performed like professionals and really made this evening a success.

We wish to thank everyone for their support and contribution to this event. We were able to raise over $1,300 from our prize tables and silent auction which contributed greatly to our overall profit of just over $5,000. These funds will assist in establishing our chapter website and in advertising and promoting future public education meetings in this area.

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Chapter coming events

Free admission – everyone welcome

Burlington/Hamilton

Location: *The Hamilton Spectator* Auditorium, 44 Frid Street, Hamilton. Free parking.

- Wednesday September 24, 2003. Display 6:30 pm, meeting 7:00 pm. **Dr. William Harper**, Endocrinologist, **Dr. Doron Sommer**, Surgeon, **Dr. Karen Gulenchyn**, Nuclear Medicine (all of Hamilton Health Sciences), **Tom Smiley**, Dell Pharmacist. Topic: *Thyroid cancer - thyroid nodules, diagnosis, treatment and aftercare*. **Rita Banach**, President of Thry'vors, will speak about patients' experiences.

Sponsored by Dell Pharmacy, Hamilton Health Sciences, Theramed Corporation and *The Hamilton Spectator*.

For more information or to register call: (905) 577-2433, 1-866-377-4447 or (905) 381-0475.

Location: Milton Seniors Activity Centre, 500 Childs Drive, Milton.

- Monday September 29, 2003. Display 6:30 pm, meeting 7:00 pm. Speaker: **Dr. Gavino Perez**, Hamilton Health Sciences. Topic: *Thyroid disease is real, know the facts*.

Sponsored by Halton Healthcare Services and Abbott Laboratories, Ltd. To register call: Halton Healthcare (905) 338-4379.

Location: Burlington Art Centre, Shoreline/Rotary Lakeshore Room, 1333 Lakeshore Road, Burlington.

- Tuesday November 4, 2003. Display 6:30 pm, meeting 7:00 pm. Speaker TBA. Topic: *Graves' hyperthyroidism and Graves' eye disease.*

For information call: (905) 577-2433, 1-866-377-4447 or (905) 381-0475.

Cowichan

Location: The Beban Park Centre, Nanaimo.

- Saturday September 27, 2003, 1:00 pm to 3:00 pm. Speaker and topic TBA.

For information call: (250) 245-4041.

Kingston

Location: Ongwanada Resource Centre, 191 Portsmouth Avenue, Kingston.

- Tuesday October 21, 2003, 7:30 pm. Speaker & topic TBA.

For information call: (613) 545-2327.

London

Location**:** Central Library, Galleria, 251 Dundas Street, London. Two hours free parking for library patrons.

- Tuesday September 16, 2003, 7:30 pm. **Dr. Merrill Edmonds**, Endocrinologist, St. Joseph's Health Centre & chapter medical adviser. Topic: *What does the thyroid do?*
- Tuesday, November 18, 2003, 7:30 pm. **Dr. Malcolm Arnold**, Cardiologist, London Health Sciences Centre, South St. Campus. Topic: *The heart and the thyroid: an intriguing partnership*.

For information call: (519) 649-5478 or visit our new website at www.thyroidlondon.ca.

Toronto

Location TBA.

- Saturday, September 20, 2003, 2:00 pm. Education meeting and AGM. Speaker and topic TBA.

For information call: (416) 398-6184.

Chapter news . . . continued from page 8

London chapter's 3rd annual "Touch of Spring" Fashion Show

Left to right, Jacob Burrows, Jenna Corrin and Danielle Nadeau

Left to right, Tina Jamieson, Jack Foote and Anne Reinhart

Ottawa

The Ottawa Area Chapter recently held two informal orientation sessions for new volunteers to get acquainted personally and to learn a bit about the history and goals of the Foundation. We also discussed the positions open that would match the interests of the volunteers.

There was great interest in the videotapes of Dr. Volpé discussing autoimmune thyroid disease. Patrick Bouthillette kindly offered his home as the venue for the friendly get together. We are happy to welcome some young and energetic volunteers to the chapter.

On Saturday, June 14, the Ottawa chapter had a display booth at the popular Parkdale Market, a very colourful spot, ideal for displaying our wares. Later in the summer we plan a potluck supper and planning session to get ready for fall chapter activities.

Moncton

The Moncton chapter held its first meeting in many years on Monday June 23. The guest speaker was Rhoda Boyce who spoke on *Thyroid and your body.* Due to the late summer date, attendance was low but there were three national past presidents in attendance: Joe Boyce, Irene Britton and Donald McKelvie, plus Don's wife Marie. A meeting is scheduled for the fall. In the meantime there is a call for volunteers to help with the chapter. Please call (506) 856-5121.

Montreal

The Montreal chapter's 7th Annual Art Show and Sale took place in early April. We sold paintings, cards and bookmarks. Three paintings were donated by Sharon Goodman, Rita Szerszen and Joyce Pratt. The happy winners were Vera Easey, Michael Colouri and Mattia Sutera.

We are looking forward to the next season. Have a great summer. See you in the fall.

My hyper/hypo story

Sylvia Shiell

by
Sylvia Shiell

In 1998, I had the experience of a tour in Bosnia with the Canadian Armed Forces. I went over with 1RCR out of Petawawa in F Company, which was the Administrative Company. I was a Cpl (Reserve) EME (Electrical Mechanical Engineer) and I kept my rank when I transferred over to the 'C' class (regular force). Working in the tool crib rather than on the vehicles used my computer skills more effectively. I categorized, computerized and cross-referenced all the tools in the crib, in the toolboxes and all the parts in the cage. This is where the saga begins.

I have always been very slow to anger, never been a fighter, one who avoided confrontation at all costs and generally talked my way out of any situation. I will not go into detail of what stresses there were; there just isn't enough room in the journal. Suffice it to say, I had screaming fights, something totally out of character.

I suffered an injury in Bosnia. Nothing so romantic as in the line of fire, I was running down a mountain in PT (physical training) and tore a tendon in my knee. That was in March of '98 and it is the beginning of the physical symptoms that made me think there was something wrong. The knee would not heal. I was on light duties for the rest of the tour.

I also noticed that when I stood at attention, my legs would shiver or shake ever so slightly. I could not stop them from shaking. I was losing strength and I became fatigued very easily, not sleepy, but as if I was running out of gas.

Upon my return to Canada, the final straw indicating something was wrong with me was a screaming, cussing fit I had at an insurance company. I immediately went to my doctor and said there is something wrong with me.

My mother has Graves' disease with severe eye involvement. I struggled all through her illness getting physicians to look at her, fix her; I listened to and had things clarified so we both knew what was going on. So you would think I would recognize the symptoms in myself. Graves' disease manifested itself in a different way with me. I did not lose weight or have the fast heartbeat. I was very weak, exhausted all the time, had brilliant ideas and went 200 miles per hour all the time. But that was my nature. Only the blood test told the true story. My numbers were so high they tested me four times to make sure they were accurate. Needless to say, I had my thyroid eradicated immediately with radioactive iodine (RAI). Imagine going from "I can conquer the world" to " I can't lift my toothbrush" in two months. That's what happened, and that's where I stayed regardless of medication.

I am very fortunate to have an endocrinologist who listens to me as well as the blood-work. We tried the T4's, Eltroxin and Synthroid with no positive change. I am one of the few people who cannot break down the T4 to T3. Cytomel was my lifesaver. I noticed a difference in my headspace within a day. It was so nice to come out of the fog.

However, the fatigue stayed and became more debilitating. I stopped walking to the bus because I would become so exhausted in my legs that they would just stop working. I started to ride my bike, but even that became too much so I ended up buying a car to get to school. I was studying for my Bachelor of Education to teach art at the secondary level. I managed to get through the schooling side of the degree, but in the middle of my practicum I had to take a leave of absence to have a total hysterectomy. All through this, we were still trying different amounts of T3 and exploring every aspect of alternative causes for the fatigue.

Thyroid eye disease started in January of this same year. As soon as I was diagnosed, I quit smoking and looked at what stress I had in my life that I could eliminate. Fortunately, my left eye stopped protruding when I took the break for the hysterectomy.

I finished my practicum in the fall of 2000 and started my Masters in Art Education in January of 2001. I also started being a Teacher On Call (TOC).

I was beginning to admit that I was slowly losing more and more mobility. I kept excusing it with a multitude of reasons.

In the fall of 2001, I got a part time teaching position teaching Auto CADD, Photoshop and 3D Studio Max. I had experience in all these subjects but really had no lesson plans prepared, nor did I know enough to teach without really learning more about the program. I managed to stay a lesson or two ahead of the kids.

This is what wore me down. This is when I realized I would never be able to do the same amount of 'work' that I had done before. This is when I realized that I have a chronic illness; that I have an autoimmune disease that is not going to quit just because the thyroid was eradicated.

In January of 2002, my knees were so sore that I could not walk on them anymore. I got a manual wheel chair so I could continue teaching. By May I could not push the manual wheel chair so I got an electric wheelchair so I could finish teaching. By June I could not type, write or walk because the pain and fatigue in my muscles was too overwhelming.

I succeeded in getting my Masters in Art Education in the summer of 2002 finishing my last course by using my laptop computer with Dragon Naturally Speaking, a program that types what I say, and Photoshop to create the required visual journal, the sketches and paintings.

I took the summer off to see if doing nothing would allow my muscles to heal. I did feel less fatigued, but my muscles just atrophied.

I started back with physiotherapy in the fall of 2002 in an attempt to build back the muscle that I had lost. I was doing quite well with the physical side until my 'A' type personality took over and I pushed too hard again and caused another crash – one that I have still not recuperated from and it is now March of 2003.

I have had every test my family doctor and my endocrinologist can think of

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Common thyroid cancer gene mutation found

Researchers at the Johns Hopkins Kimmel Cancer Center have found that a single genetic mistake causes about two-thirds of papillary thyroid cancers. Their research, published in the April 16, 2003, issue of the Journal of the National Cancer Institute, may lead to new therapies that could counteract the mistake.

Hopkins researchers found a mutation of the BRAF (pronounced b-raf) gene in 68 percent (24 of 35 samples) of papillary thyroid cancers. These tumors account for about 75 percent of all thyroid cancer and occur mostly in women. "Until now, there have been no other major genetic events identified for common thyroid cancers," says David Sidransky, M.D., professor of otolaryngology and oncology at Johns Hopkins. "Our goal is to find better diagnostics and drug therapies designed to target the effects of this mutation."

The mistake involves a subtle change in the chemical bases (adenine, thymine, cytosine, and guanine) that make up DNA. The order in which these bases – or nucleotides – occur determines the information genes communicate to cells much like specific letters of the alphabet combine to form words and sentences. In the case of BRAF, the nucleotides are altered, and T (thymine) is switched to an A (adenine). The researchers found that this single coding error among more than 2000 nucleotides in the gene causes it to be stuck in the "on" position making thyroid cells continuously grow and divide, ultimately into cancer.

"Though most thyroid cancers can be cured by surgery and radioactive iodine treatments, it remains difficult to distinguish benign thyroid disease from cancer," says Sidransky. "Improvements in diagnostic tests and treatments using what we know about the BRAF mutation could speed up diagnosis and help patients survive advanced disease." Clinical trials for patients with papillary thyroid cancer who have not responded to surgery and radioactive iodine therapy are being planned.

Hopkins researchers also screened for the BRAF mutation in other cancers and thyroid tumors. They found a small percentage in lung and head and neck cancers. Six out of nine (66 percent) thyroid cancer cell lines tested positive for the BRAF mutation. No mutations were found in biopsies from 20 benign thyroid conditions and other types of thyroid cancer such as follicular, medullary and Hurthle cell. A research team at the Wellcome Trust Sanger Institute recently found the same mutation in the BRAF gene in approximately 80 percent of melanomas and some colon cancers.

Thyroid cancer affects 22,000 Americans each year and makes up about half of all head and neck cancers. The thyroid gland essentially impacts all cells of the body by regulating metabolism, chemical balance, and hormone production.

THE SIDNEY KIMMEL COMPREHENSIVE CANCER CENTER AT JOHNS HOPKINS

This research was partially funded by the National Cancer Institute. Participants of this research include Yoram Cohen, Mingzhao Xing, Elizabeth Mambo, Zhongmin Guo, Guogun Wu, Barry Trink and Paul Ladenson from Johns Hopkins; and Uziel Beller from the University of the Negev, Jerusalem, Israel.

Related web sites: Johns Hopkins Thyroid Tumor Center at www.thyroidcancer.net and Johns Hopkins Kimmel Cancer Center at www.hopkins kimmel cancercenter.org

My hyper/hypo . . . continued from page 10

to eliminate other diseases. Thankfully, they all came back negative. Our conclusion is that I suffer from complications of hypothyroidism.

The symptom that is most debilitating is the fatigue in my muscles. If I use my muscles more than they want to be used, I am wracked with pain.

I started with a specialist in rehabilitation in the fall and we have, in the last two months, used an anti-convulsant medication to alleviate the pain. It's like a breath of fresh air. I still have the fatigue, like I am working with a quarter tank of gas, but I don't hurt all over.

I am a member of a couple of thyroid bulletin boards on the Internet and I can see by the posts that I am not the only person with these symptoms. This is why I am trying to get a group of people in Vancouver. I think we would benefit from sitting down and listening to each other. I think we could benefit from a talk with an endocrinologist who can explain what those numbers really mean. But most important to me, we would know that we are not crazy, that there are others out there who are just like us…the 10% who can't just take a pill in the morning for the rest of their life.

I used to be a hard working, independent woman. Now, I cannot work, I am dependent in more ways than I want to be. Having Graves' disease has changed my life forever.

Does my story sound familiar? Can you see yourself in me? Can I help you? Can you help me?

Let's chat. smshiell@shaw.ca.

Burlington/ Hamilton Area Chapter Helpline is now a reality

Effective July 1, 2003, a chapter Helpline is available. This new system provides both a local and a toll free telephone number throughout our chapter area. This fall the telephone numbers will be listed in the telephone directories of Oakville, Burlington & Halton Region, Hamilton & surrounding districts, Niagara & St. Catharines area, Brant County & the City of Brantford.

Burlington/Hamilton members, please be generous in supporting this project

Local calls: **(905) 381-0475**

Toll free: **1-866-377-4447**

Five minute medical school

Hypo vs. Hyperthyroidism

- → Hypothyroidism (under active thyroid gland) affects:
  - i Approximately 2% of the population as a whole
  - ii As many as 15% of the population age 75 or older[1,2]
- → Hypothyroidism is statistically more prevalent in females.[1,2]
- → People with hypothyroidism often have elevated levels of cholesterol, a cardiovascular risk factor which can improve with treatment.[1,2]
- → Hyperthyroidism (overactive thyroid gland) occurs in approximately 2% of the female population in North America.[1,2]
- → Graves disease (autoimmune disease with the presence of thyroid stimulating antibodies) is the most common cause of hyperthyroidism in women between the ages of 30 and 60.[1,2]
- → Stress may lead to, or exacerbate autoimmune thyroid disease in genetically predisposed people.[3]
- → Hypothyroidism induced by thyroid hormone withdrawal for the purposes of thyroid cancer follow-up testing can last as long as 10 weeks between initial withdrawal and restoration of normal levels.[4]
- → Driving or operating machinery while hypothyroid can be dangerous,[11] and may be interpreted as a legal 'impairment', and subject to criminal charges.[5]

Thyroid Cancer

- → Thyroid cancer is the fastest growing cancer in Canada. While the total of all cancers are growing by minus 1.2% in males and 0.1% in females, thyroid cancer leads all others growing by 2.8% annually in males and 3.9% in females.[6]
- → Approximately 2,100 new cases were diagnosed in 2002, 2/3 of these in females.[6]
- → Though more predominant in females, thyroid cancer in males is much a more aggressive disease.[7]
- → Thyroid cancer has a very high recurrence rate, and may return decades after the initial treatment. This necessitates life-long follow-up testing and management. Patients should not consider themselves 'cured'.[8,1]
- → In 2003, 170 Canadians will die of thyroid cancer, demonstrating this need for persistent long-term follow-up.[6]
- → As with the discovery of the primary thyroid cancer, early detection of metastatic disease is an important predictor of outcome.[9]
- → Recently an expert consensus was published suggesting rhTSH-stimulated Tg testing alone for long-term monitoring of low-risk patients.[10] Since Tg testing can be performed outside of the hospital, unlike whole body scans, thyroid cancer follow-up with stimulated Tg testing can proceed as scheduled in ***SARS*** affected areas.

Thyroid Nodules

- → The thyroid gland is not usually noticeable unless it is enlarged. Thyroid nodules are lumps or bumps on the thyroid.[1]
- → Statistically the lifetime risk for women of developing a nodule is 5-10%. By age 75, about 9% of women have nodules that you can see or feel, however when tested with ultrasound, which is more sensitive, thus number rises to 35%.[1]
- → Nodules may be solitary, or there may be several (multinodular). Multinodular goiters are three times more common than solitary nodules.[1]
- → Most nodules are found by chance and are no reason for concern, however should be checked. [1]
- → Nodules greater than four centimeters in size are conspicuous, and more likely to be malignant. If the nodule appears to be growing rapidly and is accompanied by hoarseness, the risk of cancer is greater.[1]

References:

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8 Mazzaferri, Kloos – Thyroid 10 (9) p.767-778, 2002.
9 Schlumberger – NEJM 338, p.297-306 1998
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Statistcs compiled by Theramed Corporation

Self Examination

All it takes is a simple test. Learn how to do a self-exam. It can save your life.

Necessary equipment: a cup of water and a mirror (with a handle, if possible).

Steps:

1. Hold the mirror and locate the area above your collarbone and below your voice box or "Adam's apple" This is where your thyroid is located. Note: The thyroid is a little higher up in a women's neck than in a man's neck. The Adam's apple is the bump that you can see in most people; it is normal.
2. Tilt your head back so that your neck is more exposed and focus the mirror on this area.
3. Take a drink of water.
4. As you swallow, watch the thyroid gland. Swallowing makes the thyroid go up and down. See if there are any lumps, bumps or bulges of the thyroid.
5. Repeat this test several times until you are certain.
6. If you note any lumps or any change from a previous test, consult your doctor.

Foundation's mailbox

I can no longer subscribe to a publication that only covers the views of conventional medicine and receives financial support from a drug company.

My personal experience with the endocrinology specialty has been less than satisfactory. I know few hypothyroids who are well on the minimal doses of T4 prescribed by endocrinologists today. Desiccated thyroid, time release T3 or Cytomel are rarely mentioned as alternatives to T4 if at all. Partial cellular resistance or general thyroid hormone resistance is another area that doesn't get covered by thyrobulletin. Contrary to the insert 'Know your TSH' there is no blood test that tells you what's happening at the cellular level making of course the perfect TSH test for diagnosing hypo or hyperthyroidism perfectly flawed. People are becoming more educated on thyroid disease via the Internet and by all the excellent books that are currently on the market. No longer will we accept a diagnosis of chronic fatigue syndrome or fibromyalgia after conventional medicine has removed or blasted our thyroids. In all fairness, the Thyroid Foundation of Canada should also publish literature that goes against the grain of convention. The Broda Barnes Research Foundation would be a good place to start.

Ms. H. Strachan, Winnipeg, MB.

Ms. Strachan is unhappy with the fact that we accept sponsorship for thyrobulletin from several pharmaceutical companies, and she is not alone in holding that position. She also questions the Foundation's editorial policy of not reporting non-traditional treatments and medical practice. I believe strongly in the right of members to disagree and these pages are reserved for dissenting viewpoints.

At one time we would not have considered accepting such sponsorships , but times change, situations change. In this day and age I believe it is to everyone's benefit to create win-win situations. Collaborating with stakeholders allows us to continue delivering our message. Without the support of our sponsors we would not be able to publish and distribute thyrobulletin. Our quarterly publication, now read by more than 4,500 members, health care professionals and the general public, is an important source of educational material and other information regarding the Foundation.

The question of 'conflict of interest' immediately comes to mind. I can assure you that the content of thyrobulletin is still controlled entirely by the Foundation. We continue reporting what is happening in the medical community regarding thyroid disease, how thyroid disease is treated, which medications are currently prescribed, as well as the news concerning those medications.

Ed Antosz, President
Thyroid Foundation of Canada

Firstly, desiccated thyroid is actually an acceptable from of treatment, but is quite unnecessary. There is absolutely no evidence that it is better than purified synthetic Thyroxine. Thyroxine converts to T3 in the body, and this is virtually invariable. If one measures the levels of T3 in a person taking T4 alone, the levels of T3 are normal, and are generally in the middle of the normal range. Thus, patients are in effect receiving T3 when they take purified synthetic Thyroxine.

There is no need for time released T3 as T4 has a half life in the body of seven days, as it slowly converts to T3.

Partial resistance to thyroid hormone or generalized hormone resistance is a well-known phenomenon in very rare cases. It generally can be recognized by elevated levels of T4 and T3 combined with elevated levels of TSH. We do see it from time to time but it is quite rare. The TSH test is not as flawed as this correspondent seems to think. If all tests of thyroid function are normal, including TSH, T4 and T3, then thyroid function is truly normal.

The Broda Barnes Foundation is not a good place to start; this Foundation believes that low basal body temperatures are actually a measure of thyroid function. This is simply untrue. Most patients with low basal body temperatures turn out to have normal thyroid function. Conversely, patients with mild but proven hypothyroidism (with high levels of TSH) may have normal body temperatures. Of course, the problem is that many symptoms of hypothyroidism are nonspecific.

If one makes a person hyperthyroid with inappropriate T3 or T4 treatment, this may lead ultimately to cardiac arrhythmias and osteoporosis. There is much bad treatment 'out there' which may have deleterious consequences ultimately.

I know this information will not influence the already convinced. However, I would like the reader to know that all thyroid associations throughout the world hold the same views as I have just espoused.

Robert Volpé, OC, MD, FRCPC, MACP
Medical Adviser

*****

Thank you very much for your help in getting my story into the last issue of *thyrobulletin*. I sent $50 as a small donation to the Foundation. I have made many copies of the article and am asking for help in this important work.

I am terribly sorry not to have asked you to mention Celia Clark's help in typing my story and forwarding it on the Internet. Without her I could not have managed.

Anna D.M. Bill, Elmira, ON

James (top) and brother Christopher

Thanks to the Thyroid Foundation of Canada for educating and informing my Auntie Dorothy about thyroid disease. She was recently diagnosed with hypothyroidism and now, after taking medicine, she is happier, less anxious, thinner and sleeping better.

A friend who is a member of the Thyroid Foundation suggested she review your website to see if she might have a thyroid dysfunction. It was a great tip, she found your website information very beneficial and full of comforting information.

My little brother Christopher and I had our thyroid TSH level checked when we were born. The doctor told my mom and dad we were healthy. Thanks for making my family well.

Do you know how healthy your thyroid gland is?

Love, James, Richmond B.C.

Metastatic thyroid cancer – five years later

by
Diane Patching

It is five years since my husband, Wally, was told by his surgeon and endocrinologist that his hemithyroidectomy had indicated thyroid cancer and that the rest of the gland must be removed. This was a complete surprise since none of the previous testing including fine needle biopsy had been positive for cancer.

Both doctors tried to soften the blow by saying that this was the best kind of cancer to have and after surgery, a little drink of radioiodine would get rid of it and it wasn't fatal; he'd live to a ripe old age and probably die from a heart attack or stroke. Reassuring words to be sure, but unfortunately these learned gentleman were mistaken in this case. I know that doctors mean well when they tell patients that thyroid cancer is 'good' but if only they would add 'in most cases' to their little speeches it would go a long way to lessen the feelings of betrayal that occur when their words belie them and it would also improve the trust necessary between doctors and patients as treatments continue.

However, Wally is no longer seen by these doctors. He was sent to London, Ontario for his 'little drink' and after a dozen or so not so little drinks of radioactive iodine, he still exhibits thyroid cancer and has never had a clean scan. Many people find this hard to believe, since this is so often publicized as the 'good cancer', easily treated and cured. Fortunately for many this is true: but not for all.

Wally tolerated the therapy well initially but as time passed, he found the hypothyroid period which had to be endured before the treatments were given, increasingly harder to tolerate. At first he made a joke of it and said that he now knew what it felt like to be an old man as his bodily functions slowed down and he stumbled around. It also didn't help that for the last two weeks of being hypo he would be on a low iodine diet which did not allow for many of the things he preferred to eat. Being hypo helped solve that problem because it suppressed appetite and the whole digestive process slowed down resulting in severe constipation. Memory loss was evident at these times and words and names would be forgotten. I don't know what would have happened if Wally wasn't already retired; he couldn't have performed his job.

The last time Wally was hypo from thyroxine withdrawal was in 2000 and he ran into trouble when his kidneys began to fail and his calcium levels rose. His parathyroids were damaged during surgery and he has had seesawing calcium levels ever since. Wally was unable to walk straight and I was afraid of him using the stairs so we opened up the sofa bed and lived downstairs for several months. During this time Wally's vision was affected and he was unable to focus enough to read the newspaper until late in the day. Of course he was seen by the ophthalmologist who blamed the hypo condition. A usually very active person, Wally was bedridden for weeks recovering and even today he cannot believe how weak he felt and how he was unable to walk properly.

"The last time Wally was hypo from thyroxine withdrawal was in 2000 and he ran into trouble when his kidneys began to fail and his calcium levels rose."

What would happen next, we wondered. The radioactive iodine (RAI) therapy required a high TSH level obtained by stopping the thyroid hormone and Wally was told he could not go through this again, his body was too vulnerable. Since this cancer had metastasized to lungs and several skeletal areas, treatment was vital to help slow down the spread.

He had previously volunteered for a chemotherapy study using an infusion of 5-fluorouracil, epirubicin and carboplatin as an adjuvant to the radioiodine treatment. It was hoped that there would be a synergistic effect which would kill the cancer cells but they decided that it might cause perforation of Wally's stomach when he drank the radioiodine. They had believed the iodine was injected not ingested.

Dr. Al Driedger suggested that Wally's TSH be raised by a couple of injections of a new product he was using, a recombinant human thyrotropin, Thyrogen. This sounded too good to be true. It was hard to comprehend that instead of six miserable weeks of thyroxine withdrawal, plus more weeks of waiting for the TSH to get down to a suitably suppressed level, a couple of injections of Thyrogen would enable Wally's RAI therapy to continue. Hard to believe, but it worked and no side effects were noted.

Thyrogen was not approved for general use by Health Canada at this time but was available via the Special Access Program and Wally took part in a compassionate use study. Because Thyrogen acts quickly to raise and lower the TSH, the RAI treatments were planned at three month intervals. This was not always possible since his blood counts were affected and he has had three rounds of external radiation for the bone metastases. The important thing is that his treatments can be continued, thus buying more time. A cure is not expected due to the proliferation of bone involvement so perhaps you may now understand my aversion to the 'best cancer' label. Of course, things could always be much worse, Wally's cancer could be non-avid for iodine and radioiodine would have no effect, which limits treatment considerably.

We are grateful for all the assistance that Wally has received, particularly from Dr. Al Driedger in London who respects his patients and works tirelessly for them.

Another excellent source of support has come from Thry'vors and I would recommend this group to anyone who has any form of thyroid cancer. There is a wealth of information in the files and many kind, considerate members who are so willing to offer the benefit of their experiences. There is also a more detailed tale of Wally's adventures in thyca land on the listserv there and he wasn't known as Wally Murphy for nothing : Murphy's Law dogged him along this journey, it has not all been smooth sailing but as mentioned previously, things could be worse and we must dwell on the positive aspects of our life and make the most of them.

Wally is now 63 years old. He used to be a long distance runner until his knees told him otherwise, so he has tried to keep fit while on this thyroid cancer trip by using a rowing machine and when a sore

continued on page 15

An open letter to the husbands of Graves' disease patients

by
David Bos

This letter is to all of us who are or were married to someone with Graves' disease. It is a letter from my heart as I know of no other way to talk about it. If in some way it speaks to those of you who are now struggling or have struggled with the loneliness, the frustration at the lack of answers, the inability to help the ones you love, having to make major decisions without your partner, or going through the pain of divorce because of a disease very few understand and even fewer still can relate to, then it will have been worth exhuming painful memories that time was mercifully putting to rest.

I've heard that the divorce rate sky rockets when someone has Graves' disease. I am not surprised. This disease works to challenge every reason you had for being married and forces you insidiously to get to the bottom line – that a marriage exists only because you are willing to remain committed to your partner, regardless of anything else.

In a lot of ways my wife and I were fortunate; she was diagnosed with Graves' disease after approximately nine months, at least that is the closest she and I can pinpoint when she first began to experience the symptoms we now associate with Graves'. During that time, however, while I always knew my wife loved me, frequently who I was married to was not my wife.

One aspect was the mood swings, the unexpected outbursts of anger and accusation, the unexplainable crying. This took the most work for me to deal with emotionally. I know I unintentionally do or say things that irritate her from time to time. But when compared with how we usually handled these issues, the anger and crying was out of proportion to the crime and it came with no warning. Unfortunately I found myself putting up a wall between us for protection and I hated the estrangement. I became increasingly on guard when with her. I didn't want to be hurt. We've been married many years and she knew me well enough to know how to get in deep with her accusations. I detested the alienation but felt caught in a 'Catch 22' – be on guard to mitigate the hurt and lose the closeness in the relationship. Remain open and get hurt. Fortunately the outbursts happened and then dissipated quickly but only recently has the 'being on guard' begun to melt.

Another was the feelings of impotence; being powerless to change the circumstance regardless of what you did. I always thought my wife was beautiful and while she is attractive physically, her beauty to me has always had little to do with her looks. I enjoy the way she thinks and what she thinks about. When we talk, I learn something. I enjoy watching her meet people. I love hearing her laugh and am frequently in amazement at her ability to laugh regardless of the circumstances. Together we've been through some amazing challenges in life. Her indomitable spirit is what got us through them. While she was going through the worst of the disease, Graves' took all that away. All I could do was stand by and watch. Nothing I did changed anything.

She had constant headaches from morning to night and over-the-counter medication didn't help. She hurt every time she blinked her eyes. Her feet were frequently so swollen they wouldn't fit into her shoes. The puffiness around her eyes and 'bug-eyed' appearance was uncomfortable for others to see. My chest ached as I watched people, who previously were attracted by her vivacious personality, now avoided her altogether or talked with her in a stilted fashion. I watched her withdraw. I was watching the love of my life shrivel and die while being imprisoned in the role of bystander. All I could do was hold her and cry with her when the unrelenting discomfort proved to be too much.

Three and one-half years have now gone by and the nightmare has finally come to a close. The disease went through its cycle and stabilized. My wife has now had corrective surgery to repair much of the physical damage of the disease. She still sleeps with a strip of plastic wrap over her eyes to keep them from drying out during the night and her feet are still swollen although less so. Mostly she has returned to living with that special brand of vitality which I so love. She is laughing again.

Where do you turn when your whole world is turned upside down? How do you cope with a situation of changing emotions, many questions, few answers and no idea when it will end, if ever? While I survived Graves' disease, I don't think I took particularly good care of myself emotionally during this time. I mostly did my 'guy' thing; I didn't talk about it to anyone. It didn't seem appropriate to talk to my wife, my usual confidante. She already had a full plate without my 'stuff'. What about talking to other men? Mostly I didn't. Occasionally I would talk about the topic when I was desperate and someone asked. But mostly, while I found some willing listeners among my friends, these times were never particularly satisfying. They would sympathize but had little or no experience with which to relate. This whole issue of 'where does the husband of Graves' go for help' is one area I would now do differently. I would take the time to find other men in the same predicament and I would talk to them. I would know I was not alone.

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Metastatic . . . continued from page 14

shoulder prevented this, he got a treadmill. He retired at an early age and our retirement project was raising Clydesdale horses which gave us much satisfaction. We no longer do this but keep a couple of Clyde geldings around; it is hard to give them up and we'll keep them as long as possible.

Wally and I have been married for over forty years and, as you may imagine, I want him around as long as possible too! We both hope that the aggressive radioiodine treatments enabled by Thyrogen, backed up by external radiation, will provide more years together.

Diane and Wally Patching live on a farm near the village of Dundalk, Ontario. Diane is a member of Thry'vors and is the publicity chair for that organization. Diane is also a member of the Thyroid Foundation of Canada. Wally had external beam radiation to his neck and for a while he was unable to eat or drink, but he refused to go to hospital so he could be properly hydrated. Wally is doing alright now and waiting for his next radioactive iodine treatment.

Iodine deficiency in America

Lawrence C. Wood, MD, FACP
President, The Thyroid Foundation of America, Inc.

by
Lawrence C. Wood, MD, FACP

In our last issue of *The Bridge* [quarterly publication of The Thyroid Foundation of America, Inc.] we talked about the problem of iodine deficiency reappearing in the United States, with special concerns for pregnant women who need the iodine to make proper amounts of thyroid hormone for their babies. Since then I spoke with Dr. Stephanie Lee, Associate Professor of Medicine and Endocrinology at the Boston University School of Medicine, who has had a long-standing interest in iodine deficiency. It had been my impression that a big part of the problem has been that farmers have stopped cleaning the udders of their milk cows with Betadine solution which contains a large amount of iodine. This apparently is not true.

Dr. Lee's report:

Iodine is in seafood, iodized salt, egg yolks and milk products (from iodine supplementation of cattle feed and Betadine udder washes). The reduction in iodine intake in America is a combination of the changes in food manufacturing and eating habits of Americans. Iodized salt was taken out of manufactured foods in the 1960s - none in canned or frozen foods. Even salty foods like potato chips have no iodine (I actually tested this). In addition, for good health we are avoiding salt and eggs.

Although most breads do not use iodate conditioners, there is one large conglomerate that does – Sunbeam bread, for example, contains about 325 micrograms of iodine per slice! And only half of the salt sold in supermarkets is iodized.

As there are more families with both parents working, home prepared foods are less common and I think this explains why the iodine excretion is low in women of childbearing age (20-40). The iodine content goes up with age probably because that population is still cooking with iodized salt. Current research indicates that 23% of American women in their 40s have moderate iodine deficiency (less than 50 mcg iodine per gram of creatinine in the urine). This increases their risk of goitre.

The easiest solution may be for most Americans to take a multivitamin containing 100 micrograms of iodine in addition to their regular diet. Our thanks to Dr. Lee for the update.

Reprinted with permission from Summer 2003, Volume 18, Number 2 of The Bridge, quarterly publication of The Thyroid Foundation of America, Inc.

Federal funding for thyroid research

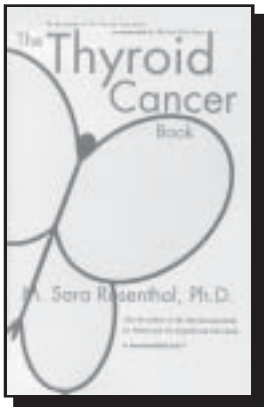
This is an excerpt from a letter written by the Minister of Health, The Honourable A. Anne McLellan, to Ms. Beverly Minnis of Ridgetown, Ontario, in response to her letter concerning federal funding for thyroid research in Canada.

. . . the Canadian Institutes of Health Research (CIHR) was created by the Government of Canada in June 2000. The CIHR's mandate is to excel in the creation of new knowledge and its translation into improved health for Canadians.

One of the CIHR's 13 institutions focuses specifically on nutrition, metabolism and diabetes, and has a mandate to support research to enhance health in relation to diet, digestion, excretion, and metabolism. This institute's mandate can include a wide range of conditions and problems associated with, for example, hormones like those affected through thyroid disease. However, no one institute is associated with thyroid research since thyroid hormones can affect not only metabolism, but also development, growth, and other physiological systems like cardiovascular, central nervous, and reproductive. Researchers in this field have associated themselves with the CIHR Institute of Nutrition, Metabolism and Diabetes, the Institute of Human Development, Child and Youth Health, the Institute of Infection and Immunity, and the Institute of Circulatory and Respiratory Health.

Currently the CIHR has committed approximately $4 million to multiyear research related to the thyroid gland and hormones.

The Thyroid Cancer Book



A welcome addition to sources of information for thyroid cancer patients is this newly published book by M. Sara Rosenthal, well-known author of many books on the topic of the thyroid gland.

This paperback book has 168 pages and sells for $24.95 Cdn, $16.50 US.

This book, and others on the subject of thyroid disorders, can be ordered and obtained promptly by calling toll free 1-888-232-4444 or accessing the Internet at www.sarahealth.com.

Thyroid Foundation of Canada

Nominations for the 2003-2004 National Board of Directors

The Foundation's nominating committee presents the following slate of nominees for the positions of each officer and member-at-large to be elected at the 23rd Annual General Meeting of the Thyroid Foundation of Canada, Friday, October 31, 2:00 pm, Holiday Inn Select, Toronto Airport, 970 Dixon Road, Etobicoke, Ontario.

OFFICERS OF THE FOUNDATION:

President: ..... Ted Hawkins, Toronto, ON

Vice-Presidents (four):

- Publicity & Fund Raising: ..... Gary Winkelman, Vancouver BC
- Chapter Orgainization & Development: .....
- Education & Research: ..... Andrew Holmes, London, ON
- Operations: .....

Secretary: ..... Joan DeVille, Kitchener, ON

Treasurer: ..... Terry Brady, Kingston ON

MEMBERS-AT-LARGE (maximum six):

Editor, ***thyrobulletin*:** ..... Rick Choma, Verona ON

Liaison, Medical Research: ..... Rita Wales, Napanee ON

Archivist: .....

..... Lottie Garfield, Toronto, ON

Nominating committee will continue to seek candidates for positions that have no nominees. Additional nominations for any of these positions may be made from the floor at the time of the election, provided the nominee has given consent to his/her nomination. All nominators and nominees must be members in good standing of the Foundation.

PLEASE NOTE:
Our slate of nominees does **NOT** include the following who are automatically members of the national board:

- the president of each chapter or a representative appointed by the chapter president, who shall be elected or appointed annually at the chapter level;
- national immediate past president.

2002-2003 NOMINATING COMMITTEE:

Mabel Miller, Chair, Gander NL

Irene Britton, Riverview NB

Marlene Depledge, Calgary AB

Ellen Garfield, Toronto ON

Donald McKelvie, Saint John NB

23rd Annual General Meeting

Friday October 31, 2003 2:00 pm

To: Each member of the Foundation

Notice is hereby given that the 23rd Annual General Meeting of the Thyroid Foundation of Canada/La Fondation canadienne de la Thyroïde will be held at **2:00 pm, Friday, October 31, 2003, at the Holiday Inn Select Airport Toronto, 970 Dixon Road, Etobicoke, Ontario** for the purpose of:

- Receiving and considering reports from the directors of the national board
- Receiving and considering the financial statements and auditor's report for the year ended March 31, 2003
- Appointing auditors for the financial year ending March 31, 2004
- Electing the executive and members-at-large of the 2003-2004 national board, and
- Transacting such other business as may properly be brought before the meeting

Members of the Foundation and the general public are welcome to attend the above meeting. All TFC members have the right to vote on all resolutions presented for approval.

In accordance with By-Law No. 1, Clause 47, each voting member present shall have the right to exercise one (1) vote. A member may vote by means of a written proxy, provided the proxy holder is a member in good standing of the Foundation. Proxy forms may be obtained from the national office. **Proxies must be received by the national office by Friday, October 24, 2003.**

Joan DeVille, National Secretary

Medications for hyperthyroidism

The most commonly used antithyroid drugs are propylthiouracil (P.T.U.) and methimazole (Tapazole). These drugs act to prevent the thyroid gland from manufacturing thyroid hormone, and thus the symptoms of hyperthyroidism will gradually subside.

You will probably begin to feel better within two weeks, you will feel a difference by six weeks, and feel well in 10-14 weeks. You will probably take the medication for 6-12 months. Your doctor will check at six months, nine months and twelve months approximately, to see if the antithyroid drug is still needed. If your thyroid gland now functions normally, your family doctor will still check you periodically to be sure that your thyroid hormone level (T4) remains within the normal range or just above (normal T4 range - 50-165nmol/L). Most patients feel better with a T4 level in the upper half of normal (110-165nmol/L).

If taking antithyroid drugs, propylthiouracil or methimazole, and you develop a rash, itching, hives, joint pains, a fever or sore throat, stop taking the drug and call your doctor immediately as you could be having an allergic reaction.

If you have any fever or infection while you are taking an antithyroid drug, your doctor will check your white blood cell count. If normal, treatment with antithyroid drugs can start again. If the white blood cell count is decreased, your doctor will use another type of treatment to control your hyperthyroidism - radioactive iodine (RAI) or surgery.

Radioactive iodine is used to control hyperthyroidism because it goes only into the thyroid gland and destroys thyroid tissue, leaving the body within a few days. Any remaining RAI decays into a non-radioactive state. Most patients need only one dose to control their hyperthyroidism: others may need additional doses.

Radioactive iodine is tasteless, and usually given in a glass of water. It is painless and no fasting is necessary – **do not be afraid of this excellent treatment.**

You should feel well within three to six months after radioactive iodine treatment. Once your thyroid level is normal yearly blood tests should be done to watch for possible development of **hypothyroidism**. Most patients will become hypothyroid.

Hyperthyroid patients

- Should avoid cough/cold medicines with decongestants as they can cause restlessness and extra stimulation of the heart.
- Should avoid stimulants such a coffee, alcohol, tobacco or chocolate while in a very hyperthyroid state.
- Should avoid excess iodine found in kelp (dulse) and some asthma medications, vitamins, cough medicines, suntan lotions, salt substitutes. **Please read the labels**.
- The preferred antithyroid drug during pregnancy, in doses lower than with non pregnant women, is propylthiouracil (PTU) and it can be used when breast feeding, as only negligible amounts actually get into the milk.
- You cannot donate blood if you are taking antithyroid medication.
- If you forget a dose of antithyroid drug or other medications contact your doctor for guidance as to the best way to resume medication.

Haloperidol (Haldol)

Hyperthyroid patients taking haloperidol may develop rigidity and the inability to walk.

Fact sheet 001, Thyroid Foundation of Canada

Monthly Draw

By renewing your membership you become eligible for our monthly draw.

Every month one renewing member will receive a book on thyroid disease.

Our March 2003 winner was:
Mrs. Shirley Kay
Peterborough, Ontario
who received a copy of
"Thyroid Problems
A guide for patients"
by Ivy Fettes, PhD, MD, FRCPC

Our April 2003 winner was:
Ronald Adams
Richmond, British Columbia
who received a copy of
"The Thyroid Gland:
A Book for Thyroid Patients"
by Dr. Joel Hamburger

Our May 2003 winner was:
Mrs. Chris Carter
Kitchener, Ontario
who received a copy of
"The Thyroid Gland:
A Book for Thyroid Patients"
by Dr. Joel Hamburger

thyrobulletin is published four times a year: the first week of May (Spring), August (Summer), November (Autumn) and February (Winter).

Deadline for contributions are:

September 15, 2003 (Autumn)
December 15, 2003 (Winter)
March 15, 2004 (Spring)
June 15, 2004 (Summer)

Contributions to:

Rick Choma, Editor
PO Box 488
Verona, ON K0H 2W0

Fax: **(613) 542-4719**
E-mail: **rchoma@sympatico.ca**

NOTICE TO MEMBERS

Your membership in the Foundation expires on the date printed on the address label on your *thyrobulletin.*

Please use the **Membership/ Donation Form** below or our secure payment system at:

www.thyroid.ca/english/ membership.html.

You may renew early – and for one or two years! You will be credited with renewal on the date that you are due to renew.

. . . Donations are always welcome.

The objectives of the Foundation are:

- to awaken public interest in, and awareness of, thyroid disease;
- to lend moral support to thyroid patients and their families;
- to assist in fund raising for thyroid disease research.

Les buts de la Fondation sont:

- éveiller l'intérêt du public et l'éclairer au sujet des maladies thyroïdiennes;
- fournir un soutien moral aux malades et à leur proches;
- aider à ramasser les fonds pour la recherche sur les maladies thyroïdiennes.

Membership/Donation Form

Awareness **Support** **Research**

All members receive *thyrobulletin*, the Foundation's quarterly publication.

Yes!
I will support the Thyroid Foundation of Canada!

Donations – ***The only gift too small is no gift at all.*** $ _____

Membership Level	One Year	Two Year	
❑ Regular	$20.00	$35.00	$ _____
❑ Senior 65+	$15.00	$25.00	$ _____
❑ Student	$15.00	$25.00	$ _____
❑ Family	$25.00	$45.00	$ _____

Total: $ _____

I will be paying my donation/membership by:

❑ Personal Cheque (enclosed and payable to Thyroid Foundation of Canada) or,

❑ Visa or ❑ MC #:_____ Expiry Date: _____

Signature: _____

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Type of Membership: ❑ New ❑ Renewal • Language Preferred: ❑ English ❑ French

We accept your membership fees and donations by mail, fax or online at our website.
All donations and membership fees qualify for a tax receipt. Please send your application and payment to:

THYROID FOUNDATION OF CANADA, PO Box/CP 1919 Stn Main, Kingston ON K7L 5J7
Tel: (613) 544-8364 or (800) 267-8822 • Fax: (613) 544-9731 • Website: www.thyroid.ca

Please Continue Your Support—We Need You!

National Office/Bureau national

Staff/équipe

Katherine Keen, National Office Coordinator/Coordinatrice du bureau national
Helen Smith, Membership Services Coordinator/Coordinatrice des services aux membres

Office Hours/ Heures du bureau

Tues.- Fri., 9:00 am - 12:00 pm/1:00 pm - 4:30 pm
Mardi à vendredi, 9h00 à 12h00/13h00 à 16h30

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Thunder Bay	(807) 683-5419
Toronto	(416) 398-6184

*The Thyroid Foundation of Canada appreciates the sponsorship of **Theramed Corporation** in underwriting the costs of producing and mailing this issue of thyrobulletin.*

Thyroid Foundation of Canada
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KINGSTON ON K7L 5J7

Has your membership expired? See Page 19