



Thyroid Foundation of Canada

thyrobulletin

La Fondation canadienne de la Thyroïde

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Thyrogen – Recombinant Human Thyrotropin Thyréostimuline humaine recombinante (Thyrogen)

In the Management of
Papillary and Follicular
Thyroid Cancer

by/par
Ernest L. Mazzaferri
MD, MACP

dans le suivi des cancers
papillaires et folliculaires
de la thyroïde

This article is written mainly for patients who have undergone treatment of papillary or follicular cancer and is intended to tell you about some new developments in the postoperative management of these tumors. Before I do this, however, you should know a few things about these tumors. Much has changed in their diagnosis and treatment over the past several decades.

The good news is that thyroid cancer mortality rates among persons living in the United States have declined nearly 50% over the past 30 years. Papillary and follicular cancers, the most common forms of thyroid cancer, have the best outcomes providing they are diagnosed early. Yet they still cause death. One large study of nearly 54,000 patients with thyroid cancer who underwent surgery in the United States between 1985 and 1995 found that 10-year cancer mortality rates were about 7% for papillary and 15% for follicular thyroid cancer. Indeed, these two typically slow-growing cancers with the “best” prognosis caused over half the thyroid cancer deaths, especially when the tumor was advanced at the time of diagnosis. Ten years of survival may seem like a good outcome – unless it is your 10 years. I believe there is room for improvement in our management of thyroid cancer.

Survival rates have been improving in the past few decades. This is partly because thyroid cancer has been diagnosed earlier

Cet article, qui s’adresse principalement aux patients qui ont reçu un traitement pour un cancer papillaire ou folliculaire de la thyroïde, a pour objectif de vous expliquer quelques progrès récents quant au suivi post-opératoire de ces tumeurs. Si vous permettez, toutefois, j’aimerais d’abord vous parler de ces tumeurs, car le diagnostic et le traitement ont beaucoup évolué au cours des dernières décennies.

Il est rassurant de savoir que, aux États-Unis, la mortalité due au cancer de la thyroïde a baissé de près de 50 % au cours des 30 dernières années. Les cancers papillaires et folliculaires, les formes les plus courantes du cancer de la thyroïde, sont ceux qui ont le meilleur pronostic, pour autant qu’ils soient diagnostiqués tôt. Ils peuvent néanmoins entraîner la mort. Selon une vaste étude qui regroupait près de 54 000 patients souffrant d’un cancer de la thyroïde qui ont subi une intervention chirurgicale aux États-Unis entre 1985 et 1995, le taux de mortalité par cancer de la thyroïde s’élevait, après 10 ans, à environ 7 % pour les cancers papillaires de la thyroïde et à 15 % pour les cancers folliculaires de la thyroïde. En effet, ces deux cancers, qui évoluent lentement en général et ont le « meilleur » pronostic, ont causé plus de la moitié des décès attribuables au cancer de la thyroïde, surtout lorsque la tumeur était avancée au moment du diagnostic. Une survie de 10 ans

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by fine-needle biopsy than it previously had been, providing an opportunity for treatment before it has spread beyond the thyroid. It is also due to the wider application of effective treatment. Proper therapy – in most cases this means surgical removal of the tumor along with the entire thyroid gland followed by radioactive iodine (131I) ablation and thyroid hormone therapy – has the potential to substantially reduce recurrence and mortality rates.

Nevertheless, recurrence rates are as high as 20% to 30% in many large studies. The most common question asked by patients after surgery is “Am I free of cancer?” This is not so easily answered because all the manifestations of thyroid cancer are typically gone after initial treatment: the neck lump is gone, chest x-rays are negative and most of the other tests show no evidence of disease. Yet the patient may still have a hidden thyroid cancer, which if treated promptly is likely to further enhance survival. Most patients therefore need close follow-up, ordinarily at least once or twice a year for several years then annually, because persistent disease may be found decades later.

Until recently, one of the weakest links in the chain of management had been testing for residual cancer after treatment. Studies now show that many late cancer “recurrences” actually are cases of persistent tumor that had fallen below the detection limits of all our tests – flying under our testing radar – sometimes for decades. Now we have an important new tool, Thyrogen (human recombinant thyroid-stimulating hormone [TSH]) that is helping us to promptly identify cancer that persists after treatment. This drug will help reduce and hopefully eliminate late tumor recurrences. Before I address how this drug is used in follow-up, you should know a few things about how the thyroid gland works.

Papillary and follicular cancers arise from thyroid follicular cells that normally siphon iodine from the bloodstream, using it to synthesize thyroid hormone from thyroglobulin (a protein made by the thyroid). Like a thermostat sensing low heat, low thyroid hormone levels trigger the pituitary to send a blood-borne signal, TSH, which prompts an increase in thyroidal iodine uptake and the formation and release of thyroid hormone and thyroglobulin (Figure 1A). TSH also stimulates malignant thyroid cells to grow and to secrete thyroglobulin, which can be measured by a blood test ordered by your physician. Thyroid hormone is given after surgery in doses sufficient to lower TSH levels to avoid stimulating growth of any thyroid cancer cells that may be left after treatment (Figure 1B).

On the other hand, high serum TSH levels are required to force malignant follicular cells to release thyroglobulin – this is the most sensitive indication that thyroid cancer persists – and to concentrate 131I for its diagnosis and treatment. Until recently this could only be accomplished by stopping thyroid

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peut sembler une bonne nouvelle... sauf s'il s'agit de votre propre vie qui est écourtée. À mon avis, il y a place à l'amélioration dans le traitement du cancer de la thyroïde.

Les taux de survie sont à la hausse depuis quelques décennies. Cette amélioration tient en partie au fait que les cancers de la thyroïde sont diagnostiqués plus tôt qu'auparavant grâce à la ponction-biopsie à l'aiguille fine, ce qui permet de traiter la tumeur avant qu'elle ne se propage au-delà de la glande thyroïde. L'usage plus répandu de traitements efficaces y est aussi pour quelque chose. Le traitement approprié – dans la plupart des cas, l'ablation chirurgicale de la tumeur et de la glande thyroïde complète, suivie d'un traitement suppressif par l'iode radioactif (131I) et d'une hormonothérapie thyroïdienne – permet de réduire sensiblement les taux de cancers récidivants (cancers qui réapparaissent) et de mortalité.

Cela dit, le taux de récurrence atteint 20 à 30 % dans un grand nombre d'études d'envergure. Après l'intervention chirurgicale, la vaste majorité des patients veulent savoir s'ils sont guéris de leur cancer. Il est loin d'être facile de répondre à cette question, car toutes les manifestations du cancer de la thyroïde disparaissent typiquement après le traitement initial : la bosse dans le cou n'est plus là, les radiographies pulmonaires sont négatives et la plupart des autres tests ne montrent aucun signe de cancer. Il se peut toutefois que des cellules thyroïdiennes cancéreuses soient encore présentes; si celles-ci sont repérées sans tarder, la survie s'en trouve prolongée. La plupart des patients doivent donc être suivis de près, généralement au moins une ou deux fois par année pendant plusieurs années, puis une fois par année, car un cancer résiduel peut réapparaître des dizaines d'années plus tard.

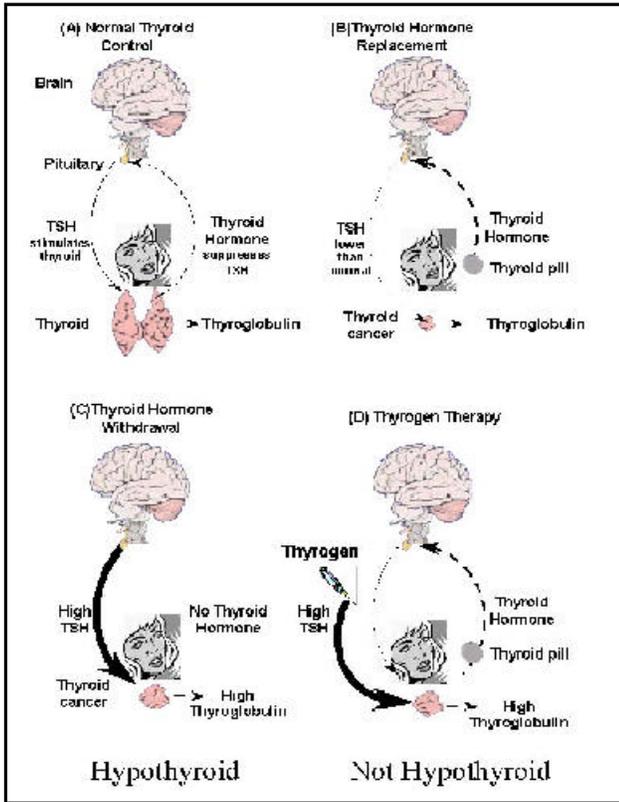
Jusqu'à tout récemment, l'un des points les plus faibles de la prise en charge du cancer de la thyroïde était les examens à réaliser pour repérer un cancer résiduel après le traitement. Les études montrent maintenant que de nombreux cancers « récidivants » sont en fait des cellules tumorales persistantes qui ont échappé au seuil de détection de tous les tests, parfois pendant plusieurs décennies... autrement dit, elles étaient là, mais personne ne les voyait. Nous avons maintenant un nouvel outil important, Thyrogen (thyréostimuline [TSH] humaine recombinante), qui nous aide à repérer rapidement un cancer qui persiste après le traitement. Ce médicament contribuera à réduire et, nous l'espérons, à éliminer les cancers qui réapparaissent à retardement. Avant de parler de la façon dont on utilise ce médicament dans le suivi du cancer de la thyroïde, j'aimerais vous expliquer brièvement certains aspects du fonctionnement de la glande thyroïde.

Les cancers papillaires et folliculaires naissent dans les cellules folliculaires de la thyroïde qui, en temps normal, siphonnent l'iode dans la circulation sanguine pour synthétiser

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Ernest L. Mazzaferri, MD, MACP



hormone therapy for about six weeks (Figure 1C), causing hypothyroidism with a myriad of symptoms such as severe fatigue and mental sluggishness that often disrupt normal activities, including driving and working. After experiencing these symptoms, many of my patients have refused further thyroid hormone withdrawal follow-up.

Now there is another option to raising serum TSH rather than withdrawing thyroid hormone. Thyrogen given intramuscularly on two consecutive days followed by a small amount of 131I on the third day and a diagnostic whole-body scan and serum thyroglobulin level on the fifth day has

I believe there is room for improvement in our management of thyroid cancer.

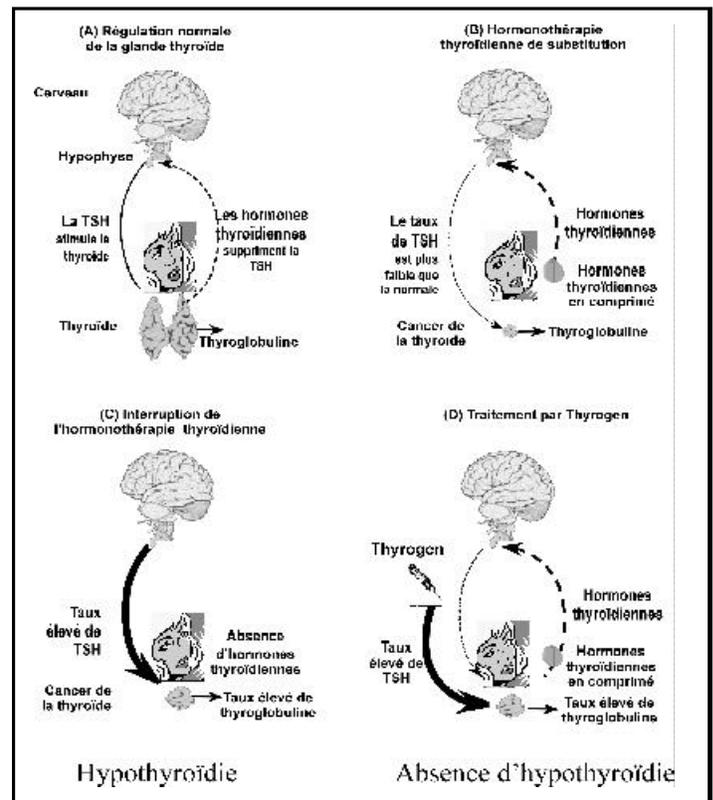
eliminated the need to stop thyroid hormone therapy during testing (Figure 1D). Although it may produce mild transient headache, two large multicentre studies showed that Thyrogen is safe and can be used in place of thyroid hormone withdrawal, giving comparable diagnostic results without producing hypothyroidism. One reason for a lack of consistent follow-up is a patient's unwillingness to tolerate thyroid hormone withdrawal. Now with the new option of Thyrogen, patients are less likely to forgo important follow-up studies, which is likely to favorably effect long-term outcomes because of the potential to identify persistent cancer early.

There is another reason that more aggressive follow-up testing is necessary. Several recent studies show that undetectable or low serum thyroglobulin levels measured during

les hormones thyroïdiennes à partir de la thyroglobuline (protéine fabriquée par la glande thyroïde). Comme un thermostat qui décèle une basse température, un faible taux d'hormones thyroïdiennes amène l'hypophyse (glande du cerveau) à envoyer un messageur dans le sang, la TSH, lequel messageur entraîne un captage plus marqué de l'iode par la thyroïde ainsi que la formation et la libération des hormones thyroïdiennes et de la thyroglobuline (Figure 1A). De plus, la TSH stimule la croissance des cellules thyroïdiennes cancéreuses et la sécrétion par ces dernières de thyroglobuline, dont le taux peut être mesuré par une simple prise de sang. Après l'intervention chirurgicale, on administre les hormones thyroïdiennes à une dose suffisante pour abaisser le taux de TSH et ainsi éviter la stimulation de la croissance de toute cellule cancéreuse qui aurait pu persister après le traitement (Figure 1B).

Par contre, pour le diagnostic et le traitement, on a besoin d'un taux sérique élevé de TSH afin de forcer les cellules folliculaires à libérer la thyroglobuline – il s'agit là du signe le plus précis de la persistance d'un cancer de la thyroïde – et à retenir l'iode radioactif. Jusqu'à tout récemment, il fallait, pour ce faire, interrompre l'hormonothérapie thyroïdienne pendant environ six semaines (Figure 1C), ce qui entraînait une hypothyroïdie et de très nombreux symptômes comme une fatigue extrême et une lenteur mentale qui perturbent souvent les activités normales, par exemple, la conduite d'un véhicule automobile et le travail. Après avoir ressenti ces symptômes, un grand nombre de patients refusent d'interrompre l'hormonothérapie pour le suivi du cancer de la thyroïde.

Nous avons maintenant à notre disposition une option qui permet d'élever le taux sérique de TSH sans interrompre l'hormonothérapie thyroïdienne. Grâce à l'administration



**Thyroid Foundation of Canada
La Fondation canadienne de la Thyroïde**

Founded in/Fondée à Kingston, Ontario, in 1980

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(1915–2000)*

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Medical Adviser – *Robert Volpé, MD, FRCP, MACP*

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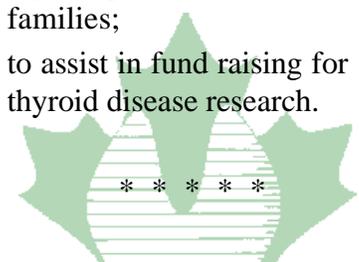
The information in *thyrobulletin* is for educational purposes only. It should not be relied upon for personal diagnosis, treatment, or any other medical purpose. For questions about individual treatment consult your personal physician.

Notez bien:

Les renseignements contenus dans le *thyrobulletin* sont pour fins éducationnelles 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.

**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.

thyroid hormone therapy does not completely assure that a person is free of thyroid cancer; to be certain of this, thyroglobulin must remain undetectable or nearly so after Thyrogen stimulation. Tumors detected by a rise in thyroglobulin after Thyrogen, when all other studies are negative, tend to be small and amenable to therapy, even those in the lung. The only downsides of Thyrogen use are its added cost and that some patients are reluctant to receive two injections. However, most insurance companies in the US cover its use, and most patients there opt for this approach rather than experience the inconvenience and symptoms of thyroid hormone withdrawal. Insurance coverage in other countries is expected to begin soon after Thyrogen receives its regulatory approval.

Thyrogen also provides an option for 131I treatment. Although not FDA or Health Canada approved for routine preparation for treatment with 131I, Thyrogen can be given to selected patients for this purpose. Studies from the Memorial Sloan-Kettering Cancer Center in New York show that 131I ablation of normal thyroid remnants can be achieved after Thyrogen preparation, producing results comparable to those with thyroid hormone withdrawal. Also, when the TSH will not rise in response to thyroid hormone withdrawal, for example in a patient with pituitary disease, or when patients have serious medical problems that preclude inducing hypothyroidism, Thyrogen has proved successful in stimulating 131I tumor uptake in patients with residual cancer.

Thyrogen provides an important option during follow-up of patients after treatment of papillary and follicular thyroid cancer and in selected cases provides a means of treating tumors with 131I that otherwise may not be amenable to this therapy. All of this can be done while the patient continues to take thyroid hormone without experiencing the symptoms of hypothyroidism. Most patients who have an undetectable serum thyroglobulin level while taking thyroid hormone should have their thyroglobulin tested under TSH-stimulation, which usually can be done with Thyrogen. This is generally done annually for a few years, and if there is no rise in thyroglobulin with this stimulation can probably be done less frequently thereafter.

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Thyréostimuline . . . suite de la page 3

intramusculaire de Thyrogen deux jours de suite, puis à l'administration d'une faible quantité d'iode radioactif (131I) le troisième jour et, enfin, au recours combiné à la scintigraphie du corps entier et au dosage de la thyroglobuline sérique le cinquième jour, il est maintenant possible de ne plus arrêter l'hormonothérapie thyroïdienne pendant les tests (Figure 1D). Bien que Thyrogen puisse occasionner de légers maux de tête passagers, deux études multicentriques de grande envergure ont révélé que Thyrogen est sûr et qu'il peut remplacer l'interruption de l'hormonothérapie thyroïdienne puisqu'il donne des résultats diagnostiques comparables sans entraîner d'hypothyroïdie. Le suivi du cancer de la thyroïde est souvent irrégulier parce que les patients ne sont pas prêts à tolérer les symptômes de l'hypothyroïdie. Avec l'avènement de Thyrogen, les patients

sont maintenant moins susceptibles de rater d'importants examens de suivi. Les résultats à long terme devraient s'en trouver améliorés, car il est possible de repérer sans tarder les cellules cancéreuses qui persistent.

Un suivi plus dynamique est nécessaire pour une autre raison. Plusieurs études récentes ont révélé qu'un taux sérique indécélable ou faible de thyroglobuline mesuré sous hormonothérapie thyroïdienne ne garantit pas l'absence d'un cancer de la thyroïde; pour le savoir avec certitude, les taux de thyroglobuline doivent rester indécélables ou presque après une stimulation par Thyrogen. Les tumeurs que l'on décèle par suite d'une élévation du taux de thyroglobuline après l'administration de Thyrogen, lorsque tous les autres examens sont négatifs, sont généralement petites et se prêtent bien au traitement, même si elles sont localisées dans le poumon. Les seuls désavantages de Thyrogen sont le coût supplémentaire qu'il entraîne et la nécessité de donner deux injections, ce qui rebute certains patients. Cela dit, la plupart des compagnies d'assurances aux États-Unis remboursent Thyrogen, et la majorité des patients optent pour cette solution plutôt que de subir les inconvénients de l'arrêt du traitement et les symptômes de l'hypothyroïdie qui en découlent. On s'attend à ce que les compagnies d'assurances d'autres pays commencent à rembourser Thyrogen peu de temps après que sa commercialisation aura été approuvée.

Thyrogen offre également une option pour le traitement par l'iode radioactif. Bien que Thyrogen ne soit pas approuvé par la FDA ni par Santé Canada pour la préparation systématique au traitement par l'iode radioactif, Thyrogen peut être administré à cette fin chez certains patients. Les études réalisées par le *Memorial Sloan-Kettering Cancer Center* à New York ont permis de constater que, après l'administration de Thyrogen, on peut avoir recours à l'iode radioactif pour supprimer les résidus de thyroïde normale. Les résultats que l'on obtient sont comparables à ceux que l'on obtient avec le retrait de l'hormonothérapie thyroïdienne. De même, lorsque le taux de TSH n'augmente pas en réponse au retrait de l'hormonothérapie thyroïdienne, par exemple, chez un patient souffrant d'un trouble hypophysaire ou de graves problèmes de santé qui rendent l'hypothyroïdie dangereuse, Thyrogen s'est révélé efficace pour stimuler la captation d'iode radioactif par la tumeur chez les patients qui souffrent d'un cancer résiduel.

Thyrogen représente une option importante pour le suivi des patients qui ont été traités pour un cancer papillaire ou folliculaire de la thyroïde. C'est également un choix approprié pour le traitement à l'iode radioactif de certaines tumeurs qui, autrement, ne répondraient pas à ce traitement. Tout cela peut être fait pendant que le patient poursuit son hormonothérapie thyroïdienne, c'est-à-dire sans qu'il n'ait à supporter les symptômes de l'hypothyroïdie. La plupart des patients dont le taux sérique de thyroglobuline est indécélable sous hormonothérapie thyroïdienne devraient faire mesurer leur taux de thyroglobuline après stimulation de la TSH, objectif qui peut habituellement être atteint avec Thyrogen. En général, cet examen est réalisé une fois par année pendant quelques années; si la stimulation ne provoque pas d'élévation du taux de thyroglobuline, sa fréquence peut probablement être réduite par la suite.

Ernest L. Mazzaferri MD, MACP, Professeur émérite et chef de la médecine, Ohio State University; Professeur adjoint de médecine, University of Florida

Thyrogen receives approval

Genzyme Canada Inc, a wholly-owned subsidiary of Genzyme Corporation, announced June 3, 2002, that Thyrogen (thyrotropin alfa for injection) has received marketing approval in Canada. Thyrogen is a recombinant human thyroid stimulating hormone intended to assist physicians in the management of their patients being followed up for the recurrence of well-differentiated thyroid cancer.

Genzyme Canada and its marketing partner, Theramed Corporation, will begin marketing Thyrogen immediately.

On May 31st, the Biologics and Genetic Therapies Directorate of Health Canada granted Genzyme Canada a Notice of Compliance (NOC) indicating that

Thyrogen has met all the requirements established under the *Food and Drugs Act and Regulations*.

Thyroid cancer patients and treating physicians have been awaiting the approval of Thyrogen in Canada. "The Thyroid Foundation of Canada is very pleased to hear that Thyrogen will now be available in Canada," said Robert Volpé, MD, FRCPC, MACP, Medical Adviser to the Thyroid Foundation of Canada. "This is a significant advancement in the way we will manage thyroid cancer. Patients will be delighted not to have to suffer through six or more weeks of being extremely hypothyroid prior to a whole body scan or Thyroglobulin test."

NOTICE TO ALL MEMBERS

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

Please use the **Membership/Donation Form** on page 19 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.

Thyrogen reçoit approbation

Genzyme Canada Inc, filiale entièrement la possession de Genzyme Corporation, annonça le 3 juin, 2002 que Thyrogen (thyrotropin alfa pour injection) avait reçu l'approbation de marketing au Canada. Thyrogen est un recombinant humain de sécrétion d'hormone thyroïdienne visé à assister les médecins dans la gestion de leurs patients qui sont sur un suivi à long terme contre les récurrences de cancer thyroïdien bien différencié.

Genzyme Canada et son partenaire de marketing, Theramed Corporation, commenceront la mise en marché de Thyrogen immédiatement.

Le 31 mai, la Direction des produits biologiques et thérapies génétiques de Santé Canada accorda à Genzyme Canada une Notification de Conformité (NOC)

indiquant que Thyrogen a satisfait toutes les exigences établies sous la Loi sur les aliments et drogues et Règlement.

Les patients de cancer thyroïdien et les médecins traitant, attendaient l'approbation de Thyrogen au Canada. « La Fondation canadienne de la Thyroïde est très heureuse de savoir que Thyrogen sera maintenant disponible au Canada » disait Robert Volpé, MD, FRCPC, MACP, le conseiller médical de la Fondation canadienne de la Thyroïde. « Ceci est une avancée significative dans la façon de gérer le cancer thyroïdien. Les patients seront contents de ne pas être obligé de souffrir à travers six semaines ou plus d'avoir une hypothyroïdie extrême avant que l'on puisse faire une scintigraphie totale du corps ou une épreuve thyroglobuline.

Thyrogen coverage

As Thyrogen is a new product many public and private insurers across Canada are still in the process of qualifying the product for coverage. However many companies have already determined that Thyrogen will be paid by their insurance plans.

Coverage of this medically necessary drug should be common but because Thyrogen is an "adjunct treatment to a procedure", some insurers may have incorrectly classified Thyrogen as a "diagnostic agent" and therefore may refuse coverage.

Some patients may need to apply for special approval with their insurer stating their medical need for care. Also, any patient facing a challenge in coverage should speak with their employer to have the insurance status corrected.

Chuckle from 'down under'

When I was first diagnosed with an overactive thyroid, I told my work colleagues that I now knew why I had become so thin and gaunt over the course of the previous few years. Some of my colleagues became quite excited. They said to me, "You have a disease where you stop taking tablets and you lose weight!! Can we please catch it from you."

I told them there was a bit more to it than that and they would not want it.

From the President, Thyroid Australia Ltd.

President's message

The Thyroid Foundation of Canada is moving forward into the next year with a new executive, several new faces and a few old faces in new positions.

To Irene Britton, now Past President, we say thanks for her many contributions and hard work for many years on behalf of the Foundation – both for the Saint John Chapter and for the national board. We also want to thank Darlene Ibey, former National Secretary and Corinne Godbout, former Legal Adviser, for their work on behalf of the Foundation.

Gary Winkelman of Richmond, BC, is stepping into the position of Vice President Publicity & Fundraising. Gary is new to the Foundation and brings with him energy and a willingness to “make it happen.” The position of Vice President Operations is also being assumed by a new face. David Morris of Kingston, ON, is taking on that role and comes to us with a background in computers and publishing. And the position which is dearest to my heart is that of the editor of *thyrobulletin*. This year Rick Choma of Verona, ON, will be performing that task as I move into the seat of president. Rick has been in media for many years and joins us with a long history of working for volunteer organizations.

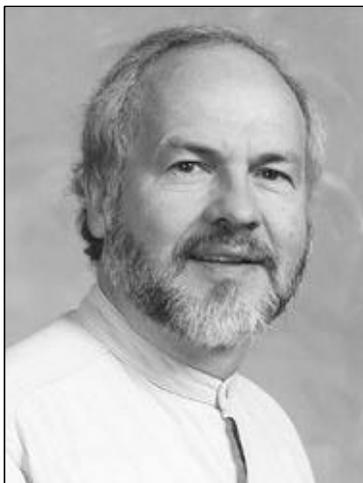
Returning to the executive are Lottie Garfield, VP Education & Research, Nathalie Gifford, VP Chapter Organization & Development, Joan DeVille, Secretary and Terry Brady, Treasurer. These tireless individuals have been involved with the Foundation for many years and have agreed to continue to serve. The Foundation will be better for their contribution.

With new energy comes new direction. But just where are we to go? Well, many years ago, in 1836 as a matter of fact, Thomas Malthus wrote: “To know what can be done, and how to do it is, beyond a doubt, the most important species of information. Next, is to know what cannot be done and why we cannot do it.”

And so we are setting out to find out exactly what we can do. There are many ideas and suggestions coming from all quarters. It is a known fact that the Foundation is in dire financial straits but that can be changed. We have been, of necessity, accepting sponsorship of issues of *thyrobulletin*. (This issue is being sponsored by **genzyme** Canada Inc.). We are one of the beneficiaries of the settlement of the class action suit involving Knoll Pharma Inc. and the marketing of Synthroid and have received \$50,000, monies which are greatly needed.

But more importantly, we are exploring new partnerships, new ways to generate revenue while still keeping the helping flavour of the Foundation intact. Our mandate is education and research and it will continue to be education and research. I honestly wish I could tell you what all of these changes will be, but the truth is that I don't yet know as change is a process that takes place over time.

Next year at this time we'll be able to look back and see a revitalized Foundation, a vibrant Foundation, a thriving Thyroid Foundation of Canada.



Ed Antosz
National president/Président national

Message du président

La Fondation canadienne de la Thyroïde se prépare pour une nouvelle année avec quelques nouveaux personnages et quelques visages familiers dans de nouvelles positions.

Nous remercions Irène Britton, maintenant ancienne présidente, pour ses contributions et son travail à propos de la fondation pendant beaucoup d'années – à la fois dans la section de Saint John et au conseil national. Nous remercions aussi Darlene Ibey, ancienne secrétaire et Corinne Godbout, ancienne conseillère légale pour leur travail envers la Fondation.

Gary Winkelman de Richmond en Colombie Britannique, prends la position de vice-président, publicité et ramasseur de fonds. Gary est un nouveau membre de la Fondation et nous apporte une énergie et une volonté à «faire ce qu'il faut pour y en arriver». La position de vice-président d'administration est aussi remplie par un nouvel-arrivé. David Morris de Kingston en Ontario, assume ce rôle et il nous arrive avec un dossier en informatique et publication. La position très proche de mon cœur est celle de rédacteur du *thyrobulletin*. Rick Choma de Verona, Ontario prendra charge de cette position en ce que j'avance au poste de président de la Fondation. Rick travailla pendant plusieurs années dans les media et se joint à nous avec une longue histoire de travail avec des organismes bénévoles.

De retour au conseil exécutif sont Lottie Garfield, vice-présidente d'éducation et de recherche, Nathalie Gifford, vice-présidente d'organisation et développement de sections, Joan DeVille, secrétaire et Terry Brady, trésorier. Ces travailleurs inépuisables participent depuis longtemps aux œuvres de la Fondation et ils ont consentis de continuer leurs services. La Fondation bénéficiera de leurs contributions.

Avec de nouvelle énergie vient de nouvelles directions. Mais où allons-nous? En 1836 Thomas Malthus écrivait que «Savoir ce qu'il faut faire et comment le faire, est sans doute le plus important espèce d'information. Ensuite, il faut savoir ce qui ne peut pas être fait et pourquoi on ne peut pas le faire».

Et alors nous parcourons notre route en recherche d'exactly ce que nous pouvons faire. Il y a beaucoup d'idées et de suggestions qui nous arrivent de toutes parts. Il est bien connu que la Fondation est en difficulté financière mais ceci peut être changé. De nécessité, nous avons accepté le parrainage pour quelques numéros de *thyrobulletin*. (ce numéro est parrainé par **genzyme** Canada Inc).

Nous sommes un des bénéficiaires du contrat de règlement dans l'action impliquant Knoll Pharma Inc. et les pratiques de marketing de Synthroid et nous avons reçu 50 000\$, fonds très nécessaires.

Plus important, nous explorons de nouveaux partenariats, de nouvelles méthodes pour générer le revenu en gardant intacte l'atmosphère d'aide qui est la Fondation. Notre mandat est l'éducation et la recherche et il continuera d'être l'éducation et la recherche. J'aimerais tellement vous dire quels seront ces changements mais franchement, je ne le sais pas encore, le changement est un processus qui ne prends place qu'avec le temps.

Dans un an d'ici nous verrons une Fondation revitalisée, une Fondation vibrante, une Fondation canadienne de la Thyroïde qui prospère.

Report from 22nd annual general meeting

The 22nd annual general meeting of the Thyroid Foundation of Canada took place on Saturday, June 15, 2002, in the Trafalgar Room, Ramada Plaza Hotel, 1677 Wilson Street, Toronto, Ontario, with 36 people in attendance.



Marlene Jelski
Toronto Chapter, Greeted all members

The meeting was preceded by a luncheon, sponsored by Kingston Area Chapter, giving those attending an opportunity to renew and make new friendships. Everyone was delighted that Dr. Volpé, the Foundation's medical adviser was able to be present this year, having recovered from a lengthy stay in hospital following several surgeries. If prizes were presented for attendance, Mabel Miller, president of Gander Area Chapter, NF, would have won for travelling the greatest distance, and for the most recent recruit, it would be Greg Mendez a Hercules pilot based at CFB Trenton, ON, who visited the national



Joan DeVille, Secretary pro tem and
Lottie Garfield, Chair pro tem

office Friday afternoon, June 14, picked up a variety of information, was made aware of the AGM in Toronto and bought a membership for a friend. She has a thyroid problem, is currently teaching in Taiwan and hopes to make thyroid disease the subject of her Master's thesis.

Greg drove to Toronto to attend the AGM on Saturday to learn all he could about thyroid disease and the Foundation. We were pleased to have with us Dr. Irving Rosen a well-known Toronto surgeon who has performed over 1,000 thyroid operations.

In the absence of Irene Britton, National President, and Darlene Ibey, National Secretary, Lottie Garfield was Chair pro tem and Joan DeVille Secretary pro tem. After lunch the Chair invited Dr. Volpé to address the group.

He spoke of the Foundation's current financial hardship with lack of government funding and competition from other charities. He noted the need for corporate support, while keeping in mind that such support must be sought in an ethical way with diligence regarding guidelines. He reported that there is an increase in thyroid cancer – 6% per year. The reasons are unknown but possibly relate to environmental factors. He spoke about various alternative medicines that to date have not been proven effective in treating thyroid disease, and can be uncertain and perhaps risky.

Dr. Volpé congratulated the Foundation on its ongoing research funding. The Summer Student Awards, in some cases, have been instrumental in interesting some young medical students to pursue a career in Endocrinology.

The future – unfortunately only a small number of people will be leaders, others will be followers. His advice – think of the good the Foundation is doing and keep at it! Dr. Volpé applauded the Foundation and said he is delighted to be associated with it.

Lottie thanked Dr. Volpé and called the meeting to order at 2:00 pm

The agenda was approved with three additions. First a presentation of a paper by Barbara Cobbe, president London Area Chapter, entitled *Where are we going – 22 years later! How many really care?* She commented on the status of the Foundation including problems such as leadership, non-functioning chapters, loss



Rita Wales
Liaison Medical Research

of membership, financial difficulties and low morale. She recommended that as a volunteer organization we need to pull together to keep the Foundation alive, and to undertake some form of fundraising. Second: Ellen Garfield reported she had suggestions for guidelines for the nominating committee but due to its length she would circulate the document by mail. Third: Nathalie Gifford requested that the Canadian Thyroid Cancer Support group (Thy'vors) be added under new business.



Nathalie Gifford,
VP Chapter Organization & Development

The standard AGM motions were presented: approval of minutes of 21st AGM, ratification of all acts and resolutions of the Board of Directors and Executive meetings, with the exception of motions 02/02 and 02/03 which were referred to the new executive for reconsideration, the acceptance of the

continued on page 9



David Morris, VP Operations

annual reports of members of the executive committee, members-at-large, chapters and office staff, the acceptance of the audited financial statements for the year ending March 31, 2002, the appointment of the firm of Secker, Ross & Perry, Chartered Accountants, Kingston, Ontario as auditors for the Thyroid Foundation of Canada for the fiscal year ending March 31, 2003.

Appointments to the following positions for the year 2002-2003 were approved: Medical Adviser, Robert Volpé, MD, FRCPC, MACP, FRCP (Edinburgh & London); Legal Adviser, Cunningham, Swan, Carty, Little & Bonham, LLP, Kingston Ontario, with David Bonham, FCA, QC, Counsel to the Firm, acting as the liaison to the Foundation; International Liaison, National President for the year 2002-2003.

Rita Wales presented motions to increase the amount of the summer scholarships and the fellowship to keep abreast of increases in the cost of living and to allocate funds for fellowship and scholarship for the coming year. Neither award had been increased since 1985. Two summer scholarships of \$4,000 each

will be offered in 2003. The 2003 Diana Meltzer Abramsky Fellowship was increased to \$35,000. No applications for the summer scholarships for 2002 were received.

Margaret Burdsall, Chair Nominating Committee 2001-2002 presented the list of nominees for 2002-2003 Executive Committee and Members-at-Large. As there were no additional nominations from the floor, the slate was elected by acclamation. See masthead for names.



Margaret Burdsall
President, Kingston Chapter
Chair Nominating Committee 2001-2002

New Business – good news. Lottie Garfield reported that the Foundation will receive \$50,000 for education and outreach as a result of the settlement of the Synthroid Class Action Suit.

Nathalie Gifford distributed Thyroid Cancer Information Packages containing information for thyroid cancer patients and physicians. These packages are the result of several meetings, with the first one in Toronto, September 2002, attended by Dr. Robert Volpé, Dr. Irving B. Rosen, and representatives from Abbott Laboratories, Ltd., Canadian Cancer

Society's CancerConnection, *genzyme* Canada Inc, The Head & Neck Cancer Foundation, Theramed Corporation, Canadian Thyroid Cancer Support Group (Thry'vors) Inc., (incorporated January 2002) and the Thyroid Foundation of Canada. Several meetings later, the contents of the package were decided upon and a group of Kingston chapter members assembled 500 envelopes. Theramed Corporation volunteered to distribute 100 of these to doctors in Ontario as a pilot project. The success of the project will be assessed in the fall.

Nathalie Gifford reported that the next issue of *thyrobulletin* is being supported by a grant from *genzyme* Canada Inc.

The location of the 2003 AGM is Toronto, Ontario.

Following adjournment, the group enjoyed a coffee break with cookies provided by Toronto chapter. In addition the chapter held a raffle to raise money to assist in offsetting the AGM costs. Chatelaine Magazine donated a basket of assorted products and Toronto chapter members donated other items. The lucky winners were: Barbara Cobbe, London, Chatelaine basket; Audrey Henry, Kingston; Dan Butt, Burlington.



Your Foundation at work

	Publicity & Fundraising
	Gary Winkelman, Vice President Publicity & Fundraising

The Thyroid Foundation is seeking your input for ideas for Publicity & Fundraising activities. The goal is to increase the profile and awareness of the Thyroid Foundation.

Your ideas are always welcome.

E-mail ideas to:

Gary.winkelman@colliers.com
(Please title your e-mail **TFC Fund Raising**)

or

Mail ideas to:

Gary Winkelman at
5891 Gibbons Drive,
Richmond, BC, V7C 2C6

Financial Statements

Thyroid Foundation of Canada/La Fondation canadienne de la Thyroïde

Year Ended March 31, 2002

Statement of Financial Position as at March 31, 2002

	<u>Operating Fund</u>	<u>Research Fund</u>	<u>Total 2002</u>	<u>Total 2001</u>
Assets				
Current Assets				
Cash and term deposits		\$236,495	\$236,495	\$ 419,153
Accrued interest		8,348	8,348	14,974
Accounts receivable	\$ 2,307		2,307	3,909
Prepaid expenses	<u>1,837</u>		<u>1,837</u>	<u>6,092</u>
	<u>4,144</u>	<u>244,843</u>	<u>248,987</u>	<u>444,128</u>
Investments				
Bonds (market value – \$225,082; \$101,877 in 2001)		<u>222,061</u>	<u>222,061</u>	<u>101,742</u>
	<u>\$ 4,144</u>	<u>\$ 466,904</u>	<u>\$ 471,048</u>	<u>\$ 545,870</u>
Liabilities and Fund Balances				
Current Liabilities				
Bank overdraft caused by outstanding cheques	\$ 7,091		\$ 7,091	
Accounts payable	14,691		14,691	\$ 30,471
Deferred revenue	<u>34,578</u>		<u>34,578</u>	<u>28,929</u>
	<u>56,360</u>		<u>56,360</u>	<u>59,400</u>
Fund Balances				
Restricted fund – research		\$ 466,904	466,904	523,210
Unrestricted operating fund (deficiency)	<u>(52,216)</u>		<u>(52,216)</u>	<u>(36,740)</u>
	<u>(52,216)</u>	<u>466,904</u>	<u>414,688</u>	<u>486,470</u>
	<u>\$ 4,144</u>	<u>\$ 466,904</u>	<u>\$ 471,048</u>	<u>\$ 545,870</u>

Research Fund Commitments (note 3)

Lease Commitment (note 4)

Approved by the Board

Member: Irene Britton, President

Member: Terry Brady, Treasurer

Statement of Cash Flow Year Ended March 31, 2002

	<u>2002</u>	<u>2001</u>
Cash Flow used for Operating Activities		
Cash received from grants and donations	\$ 71,745	\$ 83,189
Cash received from AGM	5,749	6,667
Cash received from membership fees	54,988	59,477
Cash received from books and education material	1,342	3,296
Cash received from bequests		71,000
Interest and other	29,865	27,601
Cash paid for education, services and awards	<u>(233,119)</u>	<u>(221,205)</u>
Net cash from (used in) operating activities	(69,430)	30,025
Cash Flow used in Financing Activities		
Cash purchase of investments	<u>(120,319)</u>	
Net increase (decrease) in cash	(189,749)	30,025
Cash at beginning of year	<u>419,153</u>	<u>389,128</u>
Cash at End of Year	<u>\$ 229,404</u>	<u>\$ 419,153</u>
Cash is comprised as follows:		
Cash and term deposits	\$ 236,495	\$ 419,153
Bank overdraft	<u>(7,091)</u>	
	<u>\$ 229,404</u>	<u>\$ 419,153</u>

Auditors' Report

To the Members of Thyroid Foundation of Canada, La Fondation canadienne de la Thyroïde

We have audited the statement of financial position of Thyroid Foundation of Canada, La Fondation canadienne de la Thyroïde as at March 31, 2002 and the statements of operations and changes in fund balances and cash flow for the year then ended. These financial statements are the responsibility of the foundation's management. Our responsibility is to express an opinion on these financial statements based on our audit.

Except as explained in the following paragraph, we conducted our audit in accordance with generally accepted auditing standards. Those standards require that we plan and perform an audit to obtain reasonable assurance whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation.

In common with many charitable organizations, the foundation derives revenue from donations and memberships, the completeness of which is not susceptible to satisfactory audit verification. Accordingly, our verification of these revenues was limited to the amounts recorded in the records of the foundation and we were not able to determine whether any adjustments might be necessary to donation and membership revenue and fund balances.

In our opinion, except for the effect of adjustments, if any, which we might have determined to be necessary had we been able to completely verify donation and membership revenue as explained in the preceding paragraph, these financial statements present fairly, in all material respects, the financial position of the foundation as at March 31, 2002 and the results of its operations and cash flow for the year then ended in accordance with generally accepted accounting principles.

Secker, Ross & Perry

Secker, Ross & Perry
Chartered Accountants
Kingston, Ontario
May 22, 2002

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Financial Statements

Thyroid Foundation of Canada/La Fondation canadienne de la Thyroïde

Year Ended March 31, 2002

Statement of Operations And Changes in Fund Balances Year Ended March 31, 2002

	2002			2001
	Operating Fund	Research Fund	Total	Total
Revenue				
Grant - Health Canada	\$ 15,120		\$ 15,120	\$ 34,645
AGM revenue	5,749		5,749	6,667
Membership	54,488		54,488	59,052
Donations	49,087	\$ 5,509	54,596	46,284
Books and education material	1,342		1,342	3,296
Associate member organizations	500		500	425
Summer student grant	2,029		2,029	2,260
Administration fee – research	5,063		5,063	3,563
Interest and other	1,226	22,013	23,239	30,112
Hedberg bequest				21,000
Isabel Spragg bequest				<u>50,000</u>
	<u>134,604</u>	<u>27,522</u>	<u>162,126</u>	<u>257,304</u>
Expenditure				
Education				
Health Canada projects	7,786		7,786	31,642
Chapter rebates - membership fees	22,047		22,047	23,494
Educational material	2,143		2,143	6,251
Publicity	817		817	545
Purchases for resale	389		389	1,446
Thyrobuletin (including mailing costs)	17,179		17,179	16,622
Thyrobuletin - commemorative edition				4,749
Meetings - annual	18,233		18,233	16,206
- T.F.I.				1,122
- other	883		883	3,427
Chapter development				<u>500</u>
Total Education	<u>69,477</u>		<u>69,477</u>	<u>106,004</u>
Services				
Health Canada projects				3,003
Office supplies and expenses	5,339		5,339	7,271
Postage and mailing	4,731		4,731	9,438
Professional fees - audit	1,700		1,700	1,400
Professional fees - contract accounting	3,250		3,250	3,250
Professional development - staff	180		180	280
Professional development - volunteers	250		250	1,380
Bank charges	531		531	421
Computer	2,651		2,651	3,912
G.S.T. expense	2,135		2,135	2,873
Insurance	2,405		2,405	1,537
Rent (includes services)	11,019		11,019	9,474
Salaries and benefits - office staff	39,936		39,936	39,433
Salaries and benefits - student	2,251		2,251	3,111
Telephone and fax	<u>4,225</u>		<u>4,225</u>	<u>5,248</u>
Total Services	<u>80,603</u>		<u>80,603</u>	<u>92,031</u>
Awards				
Doctoral award - CIHR		9,765	9,765	2,629
Fellowship award - T.F.C.		30,000	30,000	22,500
Fellowship award - D.M. Abramsky		30,000	30,000	30,000
Student awards		9,000	9,000	9,000
Administration - operating		<u>5,063</u>	<u>5,063</u>	<u>3,563</u>
Total Awards		<u>83,828</u>	<u>83,828</u>	<u>67,692</u>
Total Expenditure	<u>150,080</u>	<u>83,828</u>	<u>233,908</u>	<u>265,727</u>
Excess of Expenditure over Revenue	(15,476)	(56,306)	(71,782)	(8,423)
Fund balances (deficiency) at beginning of year	<u>(36,740)</u>	<u>523,210</u>	<u>486,470</u>	<u>494,893</u>
Fund Balances (Deficiency) at End of Year	<u>\$(52,216)</u>	<u>\$466,904</u>	<u>\$ 414,688</u>	<u>\$486,470</u>

Notes to Financial Statements Year Ended March 31, 2002

1. Purpose of Organization

The Thyroid Foundation of Canada is incorporated under the laws of Canada and is a registered charity. The purpose of the organization is to awaken public interest in and awareness of thyroid disease, lend moral support to thyroid patients and their families, and assist in fund-raising for thyroid disease research.

2. Significant Accounting Policies

Fund Accounting – Revenues and expenditures related to education and services are reported in the Operating Fund.

The Research Fund was established with external donations to provide financial support in helping to uncover the fundamental causes of thyroid disease.

Revenue Recognition – The Thyroid Foundation of Canada follows the deferral method of accounting for contributions. Restricted contributions are recognized as revenue in the year in which the related expenses are incurred. Unrestricted contributions are recognized as revenue when received or receivable if the amount to be received can be reasonably estimated and collection is reasonably assured.

Investments – Bonds are recorded at cost. Interest is reported as income on an accrual basis.

Capital Assets – No value is accorded to capital assets for reporting purposes. Purchases of capital assets are charged as expenditure in the year of acquisition.

3. Research Fund Commitments

An amount of \$75,000 has been committed to Research Fellowships, of which a \$15,000 balance on the 2001-2002 award is to be paid June 15, 2002. The remaining \$60,000 for the 2002-2003 award is to be paid quarterly commencing September 15, 2002. In addition, an amount of up to \$9,000 has been committed for summer student thyroid research depending on the availability of funds.

4. Lease Commitment

The foundation leases its office premises under a one year lease expiring July 2002 which calls for a monthly payment of \$835. There is an option to renew on a month to month basis.

5. Subsequent Event

Subsequent to the year end the Foundation was awarded an amount of approximately \$50,000 from a class action suit against Knoll Pharmaceutical Company.

Eileen Davidson – national office volunteer



Eileen Davidson

Eileen Davidson has been a volunteer at the national office for nearly 20 years. Originally from Basingstoke, south of London, England, Eileen came to Canada in 1953 and lived in Sherbrooke Quebec, London Ontario and then moved to Kingston Ontario with her husband in 1981. Although Eileen has never had a thyroid problem, she was an active volunteer before moving to Kingston and it was her enjoyment of working with people and keeping busy that prompted her to answer an ad in the local paper to help in the Foundation's national office.

Eileen has faithfully followed the national office through its moves to different locations, first working in the basement of Kingston General Hospital's Kidd House, then to a downtown location on Montreal Street, then to a new office in the Kingston Township and, finally, to the present location on Mack Street.

Eileen's main activity at the national office is sending out membership renewal

notices and second reminders to Foundation members each month. She folds the paper, stuffs the envelopes, sorts them for mailing and runs them through the postage meter. Occasionally, she also helps the Kingston Area Chapter and remembers the days when she joined Diana's team for mailing bees.

Eileen is a truly valued volunteer. Always smiling and working efficiently, the only 'payment' she receives for her work is the stamps from the daily mail in the national office. She is an avid stamp collector and the stamps that are not used for her collection or traded to members in her stamp club, are used to make up packages of stamps for children to encourage them to become stamp collectors.

From the staff in the national office, the National Board of Directors, and the Kingston Area Chapter, a very big:

Thank you, Eileen!

Thyroid cancer – this 'n that

Canadian Cancer Society (Excerpt – recent media release)

"A cancer diagnosis is devastating at any age", said the Honourable Anne McLellan, Minister of Health. "Health Canada is committed to the Canadian Strategy for cancer control, and to this end is working in partnership with many health organizations."

The number of Canadians between the ages of 20 and 40 being diagnosed with cancer is increasing slightly with significant increases for some cancers, according to statistics released by the Canadian Cancer Society in collaboration with Health Canada, Statistics Canada and provincial/territorial cancer registries. There were significant increased incidence rates for non-Hodgkin's lymphoma and **thyroid cancer in men and women**, lung cancer in women and testicular cancer. Incidence rates refer to the number of people per 100,000 who are diagnosed with cancer per year. **Specifically, thyroid cancer increased 6.5 percent among women and 4.2 percent among men.**

Letter to editor from **Irving B. Rosen** MD, FRCSC, FACS, (Surgical Oncology, Mount Sinai Hospital, Toronto)

"Congrats on the spring issue of *thyrobulletin*. I use photocopies of the information for patient education. How about an article on the Thy'vors (thyroid survivors). I think it would be interesting."

Thy'vors (Canadian Thyroid Cancer Support Group)

Thy'vors is a newly incorporated not-for-profit support group for those who are dealing with thyroid cancer in their lives. They strive to connect with patients and their families who want support and information about the disease. They also want to connect with physicians who are interested in receiving information

packages for patients or getting involved with local groups, and welcome additional volunteers to help build Thy'vors.

To reach Thy'vors and get involved, subscribe to their listserv at <http://groups.yahoo.com/group/Thyrvors/join>. This is a forum for thyroid cancer patients and their families to inform and support each other. People at all stages on the road to recovery, from newly-diagnosed to long-term survivors, are able to share and guide one another.

Thy'vors can be contacted at:

Email:
thyrvors@sympatico.ca

Mail:
Thy'vors
PO Box 23007
550 Eglinton Avenue West
Toronto, ON M5N 3A8

Telephone:
1-416-487-8267

Antithyroid drugs

Antithyroid drugs are given to control hyperthyroidism. They are used initially in symptomatic hyperthyroid patients to return thyroid hormone levels to normal prior to treatment with radioiodine or surgery. They are also used in Graves' disease to control hyperthyroidism for one to two years in the hope the patient will achieve a remission from the disease.

Two drugs are available in the United States (and Canada): propylthiouracil (PTU) and methimazole. Methimazole is available as a generic preparation, or the brand Tapazole. In Europe carbimazole is a widely used drug similar to methimazole.

Both drugs interfere with thyroid hormone synthesis. In addition PTU reduces the conversion of thyroxine (T4) to the more active thyroid hormone T3, a process that occurs in organs throughout the body. Prior clinical studies demonstrated that the T3 concentrations *during the first few days of treatment* fell quicker in PTU-treated patients than in methimazole treated patients, and as a result, many physicians previously preferred PTU over methimazole.

Methimazole is better

Recent studies, however, clearly demonstrate the superiority of methimazole over PTU. The serum half-life of methimazole is 4 to 6 hours: the half-life of PTU is 75 minutes. This

by
Douglas S. Ross, MD

means that it takes 4 to 6 hours to remove half the concentration of methimazole from the blood, but only 75 minutes for PTU.

Methimazole is concentrated into thyroid tissue 100-fold above serum levels, and maintains inhibitory levels (preventing formation of new thyroid hormones for up to 20 hours after a single dose, much longer than for PTU.

As a result, methimazole is almost always effective when given as a single dose, while PTU requires multiple doses daily, most commonly three times a day. Compliance is therefore better when methimazole is prescribed.

In one study comparing methimazole and PTU, the T3 level in the blood was lower after 4 weeks of treatment in the patients receiving methimazole (despite the 'advantage' that PTU prevents conversion of T4 to T3). In another study, it took 5.8 weeks for patients taking methimazole to have normal levels of both T4 and T3 in their blood, while patients taking PTU required 16.8 weeks.

Patients who receive radioiodine after a course of antithyroid drugs are more likely to have a treatment failure if they received PTU. The reason for this is not understood.

In addition, the side effects of PTU may be worse than those for methimazole. Both drugs may be associated with rashes, hives, nausea, or vomiting in up to 13% of patients. The more serious side effects include agranulocytosis (a lowering of the white blood cell count), liver damage, and vasculitis. In some, but not all studies, agranulocytosis, which occurs in 0.25% of patients, was less common when low doses of methimazole were used. Rarely, PTU can cause hepatocellular necrosis (destruction of the liver) which can be fatal: while methimazole can cause cholestatic jaundice (bilirubin is not processed correctly), a condition which is reversible when the drug is stopped. Serious vasculitis which can cause joint pain, fevers, kidney and other organ damage is a rare complication of antithyroid drugs, but almost all cases have been reported after PTU.

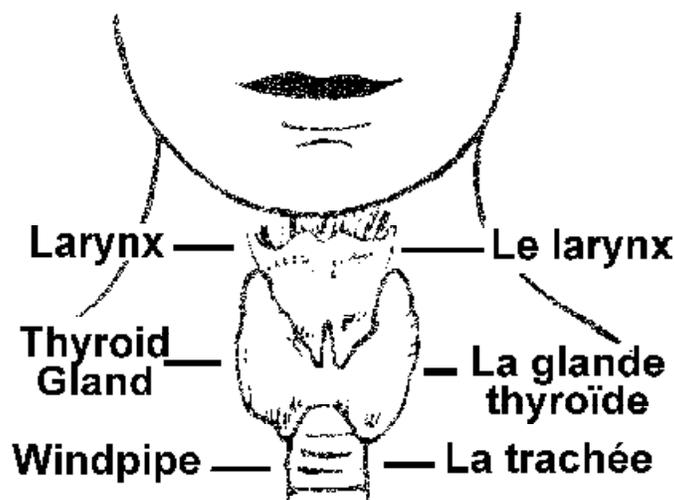
Methimazole has been reported to be associated with a rare scalp defect in neonates of mothers taking the drug during pregnancy, so many physicians prefer to use PTU in pregnant hyperthyroid patients. Less PTU is concentrated in breast milk than methimazole, although there have been no adverse reports related to the use of methimazole in nursing mothers.

Douglas S. Ross, MD, is Co-Director, Thyroid Associates, Massachusetts General Hospital, Boston. Reprinted with kind permission from The Bridge, publication of The American Thyroid Foundation.

How the Thyroid Gland Works – Just the Facts

- The thyroid gland secretes two major hormones - T4 (thyroxine) and T3 (triiodothyronine).
- These hormones are circulated to the organs of the body through the bloodstream. They affect the body's metabolic rate and cell growth.
- The thyroid "loop" begins when the hypothalamus signals the pituitary gland to release Thyroid Stimulating Hormone (TSH).
- TSH travels from the pituitary gland to the thyroid gland and triggers it to produce T3 and T4.
- T3 and T4 are released into the bloodstream.
- T3 is the active form of T4. However, T4 can have some activity on its own – it need not be entirely converted to T3.
- The "feedback loop" depends on the level of T3 and T4. When the level is correct, production of TSH levels off in the normal range.
- If there is too little T4 and T3, there will be an overproduction of TSH. The presence of a high level of TSH signals hypothyroidism. If there is too much T4 and T3, there will be a suppression of TSH, signaling hyperthyroidism.
- The TSH Assay test measures hormone levels in the blood as a marker of thyroid function. Through this simple test, hypothyroidism and hyperthyroidism are detected.

Glossary



Glossaire

Antibodies: Molecules produced by the lymph tissue to neutralize the effect of a foreign substance.

Hashimoto's thyroiditis: Hashimoto's is the most common cause of hypothyroidism. It is a disorder of the thyroid gland, most common in middle-aged women, in which the body's antibodies attack the thyroid tissue.

Hormone: Chemical substances produced by the body's glands to control the functioning of the body's organs. They are carried by the blood.

Hyperthyroidism: A disease that occurs when the thyroid gland produces **too much thyroid hormone**.

Hypothyroidism: A disease that occurs when the thyroid gland does **not produce enough thyroid hormone**.

Immune system: The body's system that protects it from foreign organisms.

Levothyroxine sodium: A man-made form of the main hormone produced by the thyroid gland. It is the most common drug for treating hypothyroidism.

Osteoporosis: A condition of depleted bone mass. The result is weakened or compressed bones that may be broken by minor injuries and/or curvature of the spine.

Pituitary gland: A gland situated at the base of the skull. The pituitary gland monitors the bodily processes and produces Thyroid Stimulating Hormone (TSH), a hormone that signals the thyroid gland to produce thyroid hormone.

Thyroid gland: A tiny butterfly-shaped gland located in front of the windpipe. It regulates your body's organs through the thyroid hormone it produces.

TSH test: A simple blood test used to uncover thyroid disease. Thyroid Stimulating Hormone (TSH) is a hormone that rises or falls with abnormal thyroid function. This test measures TSH hormone levels in the blood to detect if the thyroid is working properly.

Anticorps: Molécules produites par les tissus lymphatiques pour neutraliser une substance étrangère.

Hormone: Substance produite par une glande et déversée dans le sang, ayant une action physiologique spécifique au niveau de divers organes.

Hyperthyroïdie: Maladie découlant d'une **sécrétion hormonale excessive de la thyroïde**.

Hypophyse: Glande située à la base du crâne. L'hypophyse régularise les processus de l'organisme et produit la TSH, ou thyroïdostimuline hypophysaire, hormone stimulant la sécrétion d'hormones par la thyroïde.

Hypothyroïdie: Maladie découlant d'une **sécrétion hormonale insuffisante par la thyroïde**.

Lévothyroxine sodique: Forme synthétique de la principale hormone sécrétée par la thyroïde. C'est le médicament le plus fréquemment prescrit dans les cas d'hypothyroïdie.

Ostéoporose: État caractérisé par une diminution de la masse osseuse. Les os affaiblis ou comprimés peuvent se fracturer aux chocs mineurs ou, dans le cas de la colonne vertébrale, sous l'effet de la courbure.

Système immunitaire: Système de protection de l'organisme contre les germes étrangers.

Test de la TSH: Test sanguin simple utilisé pour déceler les maladies thyroïdiennes. La sécrétion de TSH (thyroïdostimuline hypophysaire) augmente ou diminue en cas d'anomalie de la fonction thyroïdienne. Ce test consiste à mesurer les concentrations d'hormone dans le sang pour déterminer si la thyroïde fonctionne correctement.

Thyroïde: Minuscule glande en forme de papillon placée en avant de la trachée qui régularise la fonction des organes par l'intermédiaire des hormones qu'elle sécrète.

Thyroïdite de Hashimoto: C'est la cause la plus commune d'hypothyroïdie. Il s'agit d'un trouble de la thyroïde, très fréquent chez les femmes d'un âge mûr, durant lequel des anticorps produits par l'organisme attaquent le tissu thyroïdien.



Letters to the doctor

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

The following questions were provided by thyroid cancer patients.

Overall Treatment

Thyroid cancer patients often have to see several doctors for treatment and monitoring. What can we do (or ask our doctors to do) to make sure we don't end up like footballs flying between specialists with different opinions?

This first question is the most difficult to answer, because there is no 'gold standard' to determine the expertise of a given doctor. Presumably the patient should have a general practitioner whom they respect and trust, and would generally ask this physician to refer them to a thyroid surgeon that they know, respect and have considerable faith in.

Surgery

The Thyroid Foundation of Canada Health Guide on the *Surgical Treatment of Thyroid Cancer* states that "it is best to ensure that the surgeon selected for the operation is someone who is experienced or educated in thyroid surgery." How do you determine if your proposed surgeon meets these qualifications? How do you know your surgeon is experienced? How can you ask these questions without appearing disrespectful?

If the thyroid surgeon is working in an academic centre, it would be appropriate to communicate with the Head of Endocrinology at that university and ask about the qualifications of the surgeon involved, or ask the same question of the Chairman of the Department of Surgery in that university.

When the diagnosis is thyroid cancer, what are the advantages and disadvantages of a hemithyroidectomy? Under what circumstances is a total thyroidectomy the recommended approach?

Thyroid carcinoma is generally multifocal, involving both lobes. At least 60% of the cases have these qualities. Thus, a hemithyroidectomy would not be considered adequate surgery for such cases. Moreover, if all of the thyroid tissue is not removed, then the serum thyroglobulin is not as useful for follow-up and prognosis as it would be if the entire thyroid gland was removed. Many surgeons prefer a total thyroidectomy for all cases of thyroid carcinoma. On the other hand, there is a marked increase in hypoparathyroidism in the case of total thyroidectomy, and there is only a slight difference in the mortality rates between those who have had a total thyroidectomy and those who have had a hemithyroidectomy.

Is there any particular surgical (or post-surgical) approach that ultimately minimizes the appearance of the scar? What steps can the patient take post-surgery to promote the healing of their scar and ultimately minimize its appearance?

The appearance of the scar depends to some degree upon the expertise of the surgeon, and on whether the patient has a tendency to form excess scar tissue.

Sometimes there is a reduction in parathyroid function with surgery. How long does this situation usually last? How is reduced parathyroid function monitored after surgery and how often does this testing take place? Is any particular type of calcium supplement recommended over another? At what point in time is reduced parathyroid function considered permanent?

The reduction in parathyroid function will occur if there is injury to the parathyroid glands during surgery, or to the blood supply to the parathyroid glands. This situation lasts a variable length of time depending on the above variables. Parathyroid function is

assessed by means of measurements of the serum calcium and phosphorus levels and may last days, weeks or months. Generally, some idea as to how long such an interval will be can be assessed early on in the post-operative period, and some idea of the length of this interval can be determined. If hypocalcaemia lasts for a few months, it is likely to be permanent. There are not major differences between various types of calcium, and generally the least expensive form of calcium should be purchased.

For those with reduced parathyroid function, when is supplemental vitamin D (e.g. Rocaltrol) prescribed?

When it appears that hypoparathyroidism is going to be permanent, then Vitamin D should be introduced. However, even when transient hypoparathyroidism seems to be prolonged, many physicians will employ Vitamin D for weeks or months until this interval has been completed

At what point post-surgery should the voice return to normal?

It may take weeks for the voice to return to normal. However, if there is no permanent damage done to the larynx, usually at the end of a few weeks, the voice begins to sound quite normal.

Can surgery be an option for the treatment of bone metastases? What factors determine whether or not surgery is an option? Is this type of surgery done in Canada?

If there are metastases in the neck which are amenable to surgery, then these should be removed, even if there are widespread bone metastases. Sometimes this will have an ameliorating effect on the growth of such metastases. This type of surgery can certainly be done in Canada.



Chapter news

Burlington/Hamilton

The June 4, 2002, meeting was well attended, in spite of the bad weather. VP Don Pennell gave a great presentation on behalf of the chapter and the Foundation, resulting in 14 new memberships. The special guest speakers, Sara Rosenthal and Tom Smiley, gave informative presentations appreciated by all.

I am pleased to announce that in September, thanks to Dell Pharmacy's "Living Well with Dell" Health Series 2002, we are holding first time ever meetings in St. Catharines and Brantford. Dell has 16 pharmacies throughout the area which provides the opportunity for this multi-city series.

The chapter is continuing its fundraising efforts so that we can provide members and the public with helpful information. Please support our activities listed in Chapter Coming Events.

Halifax

President Phyllis Payzant is home following a mastectomy and radiation treatment earlier in the year. Phyllis is still her usual effervescent self.

London

London chapter held its 2nd Annual Fashion Show, April 18, 2002, at the Hellenic Community Centre. This successful event was attended by 240 persons. The evening started with a delicious dinner, then 'on with the show'. We were very pleased to have support from our medical community. Dr. Tom McDonald, Endocrinologist, St. Joseph's Health Centre; Dr. Al Dreidger, Nuclear Medicine, London Health Sciences Centre and Carmen Spovirei, London Public Library started with a 'kickoff' for the Thyroid Foundation.

Dave and Jacquie from radio station BX93 hosted the show and did a great job. The models were volunteers from various walks of life, especially Dr. Terri Paul, Endocrinologist, St. Joseph's Health Centre. The children were a big hit. Planning for the 3rd Annual Fashion show is already in the works and we are looking forward to another successful event.

Another successful fundraiser for *June is Thyroid Month* was a charity barbeque held June 1 at Loblaws Wonderland Market on Southdale Road.



London chapter's 2nd Annual Fashion Show, April 18, 2002

Montreal

Montreal chapter had another busy year, with great speakers and our annual art exhibition and sale. Three happy winners of the paintings are: Natalie Guha, South Shore, won a picture donated by Sharon Goodman; M. Gerstein, Cote St. Luc, a painting donated by Joyce Pratt; Maria Storto a picture donated by Phyllis Pedacelli. Our sincere thanks to the staff at Montreal General Hospital, the artists, the volunteers and to the public for their support in making this event a success.

Saint John

Don McKelvie, a national past president, returned home after a major heart attack and heart surgery. He walked out of the hospital, smiling and thumbs up, Friday June 24, 2002.

Toronto

On April 16 the chapter participated in a health fair at the Don Mills Foundation for Senior Citizens. President Margaret Hunter organized the display and volunteers. It was a good opportunity to distribute thyroid literature to the public and to share information and experiences with the other participating health organizations. The Don Mills Foundation for Senior Citizens is a not-for-profit organization that offers a broad range of services and a commitment to a continuum of service to seniors. Thanks to Laura Mandryk, Lottie Garfield and Ellen Garfield for staffing the booth.

On May 23 a successful golf fundraising event was held to benefit Toronto chapter. Donations of \$2,850 were collected. Our thanks to Toronto

chapter founding members, Wendy and Don Forman, for suggesting the Foundation as this year's charity for the yearly event organized by a business associate.

The chapter held its AGM June 8. Due to a last minute cancellation by the speaker, a video presentation of two videotapes featuring Dr. Volpé were substituted. The tapes on hypo and hyperthyroidism were well received by the audience who chose to stay and view other tapes in the chapter's collection. Questions from the audience were fielded by Lottie Garfield, who answered the simpler ones; the more complex were gathered for referral to Dr. Volpé.

For details regarding fall meetings, call the help-line at 416-398-6184.



We need you

- ✓ consider a gift membership
- ✓ renew your membership
- ✓ consider a donation
- ✓ ask a friend to join

Visit our website at www.thyroid.ca/english/membership.html if you wish to use a credit card on our secure payment system.

Remember . . .
the only gift too small is
no gift at all!

Thank you for your past support.
Your help is needed more than ever.

Chapter coming events

Free admission – everyone welcome

Burlington/Hamilton

Location: Evergreen Apartments, 5 Tabor Drive, St. Catharines, “the Lounge” meeting room.

- Tuesday, September 24, 2002, 7:00 pm Speaker: **Bill Cuthbert**, Pharmacist, Dell Pharmacy. Topic: *Thyroid medication: your pharmacist and you*. Registration required

For information call: (905) 549 1464. In St. Catharines call Betty: (905) 937-7372

Location: Brantford, September, Speaker, Pharmacist. Topic. TBA

Location: Joseph Brant Memorial Hospital, Bodkin Auditorium, Burlington

- Tuesday November 12, 2002, 7:30 pm Speaker & Topic TBA

Gander

- Gander Area Chapter wishes to inform all thyroid patients in the area there will be an education meeting in September 2002. The meeting will be open to anyone who has an interest in thyroid disease. Details will be announced through the various local media.

For information call: 709-256-3073

Kingston

Location: Ongwanada Resource Centre, 191 Portsmouth Avenue, Kingston

- Tuesday, November 19, 2002, 7:30 pm. Speaker TBA.

For information call: 613-545 2327

Monthly thyroid discussion group

Location: Loblaws Market, Upstairs, Kingston Centre

- Fourth Sunday of each month, 3:00 - 4:00 pm. Discussion led by pharmacist Bozica Popovic. Sponsored by Loblaws Pharmacy

For information call (613) 530-3414

M. Sara Rosenthal presents: Thyroid Town Meeting – Your questions answered in plain language.

Location: Wilson Room, Kingston Public Library, 130 Johnson Street

- Tuesday, September 17, 2002, 7:00 pm. **Sara Rosenthal, PhD**, is the author of *The Thyroid Sourcebook for Women* and the upcoming *The Thyroid Cancer Book*.
- Admission at door, \$15.

Kitchener-Waterloo

Celebration: 20th Anniversary Event. Calling all past and present members to celebrate and rekindle friendships. Everyone welcome.

Location: Community Room, Albert McCormick Arena, 500 Parkside Drive, Waterloo

- Tuesday October 15, 20th Anniversary Dinner and lots of fun. Guest speaker, **Dr. Daniel Drucker**, Endocrinologist, Toronto General Hospital. Tickets: \$20 per person. RSVP by August 31, 2002.

For tickets/information call: 519-745-4475 or 519-884-6423.

London

Location: London Public Library Galleries, 305 Queens Avenue, London – **note new location in library.**

- Tuesday September 17, 2002, 7:30 pm. **Dr. Donald Killinger**, Endocrinologist, St. Joseph’s Health Centre. Topic: *Hypothyroidism*
- Tuesday, November 19, 2002, 7:30 pm. **Dr. Merrill Edmonds**, Endocrinologist, St. Joseph’s Health Centre. Topic: *Alternate therapies for the thyroid.*

For information call (519) 649-5478

Montreal

Plans are now underway for the fall. Dates are booked, speakers and topics will be announced. Please reserve the following dates, October 9, 2002, November 13, 2002, February 12, 2003, March 12, 2003

The annual art show will take place April 5 to April 11, 2003.

For information call (514) 482-5266

Parents of children with thyroid disease

Enquiries have been received from parents who have children with different types of thyroid problems who have concerns about the changes these children go through as their systems mature, e.g. puberty. They would like to exchange ideas with other parents. If you are willing to ‘talk’ to other parents, please send your name, address and/or telephone number and/or e-mail address and the kind of problem you want to discuss, to the national office.

The national office address, telephone numbers and e-mail address are on the back cover of *thyrobulletin*.

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

Deadline for contributions are:

March 15, 2003 (Spring)
June 15, 2003 (Summer)
September 15, 2002 (Autumn)
December 15, 2002 (Winter)

Contributions to:

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

Fax: (613) 542-4719

E-mail: rchoma@sympatico.ca



Letters from the Foundation's mailbox

Letter to National Office

Irene Britton, national past president and Katherine Keen, national office coordinator, spoke to a lady in France who wanted information. They asked Dr. Volpé for help and he sent a very long article that he thought appropriate for her. Following is her e-mail thank you note, translated into English by Irene Britton.

29 March 2002

ATT: Mme Katrine Keen
Mme Irene Britton

Bonjour,

Merci infiniment pour vos documents j'ai bien reçu.

Je suis extrêmement touchée par votre chaleureux intérêt. Je sais maintenant qu'en ce beau pays le Canada, une équipe professionnelle, dynamique et passionnée entoure avec beaucoup d'attentions et d'amour les malades qui en ont tellement besoin.

Avec toute mon amitié.

Béatrice Bouteleux
France

PS: je vous ferai parvenir un courrier.

29 March 2002

ATT: Mme Katrine Keen
Mme Irene Britton

Hello,

Thank you very much for the documents you sent me.

I am touched by your warm interest.

I now know that in that beautiful country of Canada, a professional, dynamic and passionate team surrounds with great attention and love those patients who need it so much.

With friendship.

Béatrice Bouteleux
France

PS: I will mail you a letter.

Letters to membership chair

Thanks for the sheet *How the Thyroid Gland Works: Just the Facts*. That is the most succinct, concise, precise, and blessedly clear explanation I've come across, and it is accurate. Congratulations to the one who wrote it and to those who felt the need for such a straight forward, needed outline. Best wishes.

S.J.

This sheet, and several others, was written by Barry Ashpole, of Barry Ashpole and Associates Inc. for the Foundation, at the request of Knoll Pharma Inc.

Thank you for your letter reminding me of the fast approaching expiration of my membership at the Thyroid Foundation.

Please be advised that I have decided not to renew my membership at the Foundation. I did find some of the information in *thyrobulletin* helpful, but I notice that the bulletin is geared to synthetic T4 users only with treatment based solely on TSH levels.

Although I believe that TSH is a good determinant of whether a patient is hyper or hypo, I do not think it is the only answer. The patient's overall well-being must be considered first, then the laboratory values provided by the assay as TSH level varies from patient to patient. Furthermore, the option of natural thyroid was never discussed in any of the issues during my year of subscription.

In the interim, I wish the Foundation the very best.

Emilia Moon-de Kemp

Letter to the editor

Thanks to thyrobulletin I have been able to diagnose myself. Sadly, doctors that I visited, couldn't, including the doctor who administered my radioiodine treatment for hyperthyroidism.

After that, I developed severe eye problems, and I had no clue what was happening to me. When I finally managed an appointment with the above noted doctor, she looked at me and said my eye problems had nothing to do with my thyroid!!! She was almost rude that I had bothered her. So much for compassionate and meaningful communication with a patient, as said in an article by Dr. Ian R. Hart in Winter, 02, *thyrobulletin*.

My suggestion – mail *thyrobulletin* to doctors in my region to educate them! .

I dare you to print this note in your bulletin!!!

Waltraud Schmidt

Monthly Draw

Renew your Membership now and become eligible for our Monthly Draw

Every month one renewing member receives a book on thyroid disease.

Our March 2002 winner was:

Ms. Martha Aldrich

Irishtown, New Brunswick
who received
"How your Thyroid Works"
by H. J. Baskin

Our April 2002 winner was:

Ms. Jackie Eccles

Vancouver, British Columbia
who received
"How your Thyroid Works"
by H. J. Baskin

Our May 2002 winner was:

Mrs. Robert Schwob

Kingston, Ontario
who received
*"The Thyroid Gland
A Book for Thyroid Patients"*
by Joel I Hamburger, MD, FACP

*A bird does not
sing because it has
an answer – it sings
because it has a
song.*

**ESTATE
PLANNING**
Will You Do It Now?

If you have not made your will yet, will you do it now? Will you remember the Thyroid Foundation of Canada?

If you plan to update your will, will you do it now? Will you help the Thyroid Foundation of Canada?

If we have helped you, will you help us help others? A bequest, an insurance policy, a tax exempt donation – will you think about it? Will you do it now?

How to stay young in 2002

Surround yourself with love.

When tears happen, endure, grieve and move on.

Laugh often, long and loud, laugh until your sides hurt.

Cherish your health. If it is good preserve it, if it unstable improve it.

If it is beyond what you can do, get help.

Remember, life is not measured by the number of breaths we take, but by the moments that take our breath away.

Don't take guilt trips. Do take trips to the mall, the country or abroad.

Keep only cheerful friends. Grouches pull you down. If you really need a grouch, there are probably family members that fill the need.

Throw out non-essential numbers. This includes age, weight and height.

Enjoy simple things – when the children are young, when the children go to college, when you retire – that is all you can afford.

Keep learning – computer, crafts, gardening, painting are a few suggestions.

Membership/Donation Form

New memberships run for one or two years from the receipt of this membership application.

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: _____

Name: _____

Address: _____

City: _____ Province: _____ Postal Code: _____

Tel: _____ Fax: _____ E-mail: _____

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/

Tues.- Fri., 9:00 am - 12:00 pm/1:00 pm - 4:30 pm

Heures du bureau

Mardi à vendredi, 9h00 à 12h00/13h00 à 16h30

Tel: (613) 544-8364 / (800) 267-8822 • **Fax:** (613) 544-9731 • **Website:** www.thyroid.ca

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Cowichan (250) 245-4041

Vancouver (604) 266-0700

ALBERTA

Edmonton (780) 467-7962

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Charlottetown (902) 566-1259

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Avalon/ St. John's (709) 368-5068

Gander (709) 256-3073

Marystown (709) 279-2499

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Ottawa (613) 729-9089

Petawawa/Pembroke (613) 732-1416

Sudbury (705) 983-2982

Thunder Bay (807) 683-5419

Toronto (416) 398-6184

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Thyroid Foundation of Canada
La Fondation canadienne de la Thyroïde
PO BOX/CP 1919 STN MAIN
KINGSTON ON K7L 5J7



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