



Thyroid Foundation of Canada

thyrobulletin

La Fondation canadienne de la Thyroïde

Volume 24, No. 1

Spring 2003



Dr. Robert Volpé

Named to Order of Canada
Nommé Officier de l'Ordre du Canada



Dr. Volpé, an internationally known endocrinologist and researcher, long time medical adviser to the Thyroid Foundation of Canada and chair of the foundation's peer review committee, has been recognized with Canada's highest honour for lifetime achievement. Dr. Volpé was named an Officer of the Order of Canada by Governor General Adrienne Clarkson on January 17th, 2003.

The first to highlight the role of specialized cells of the immune system in thyroid disease, Professor Emeritus at the University of Toronto and a former director of the Endocrine Research Laboratory at Wellesley Hospital, Dr. Volpé has been a mentor to many young scientists and physicians from around the world. The recipient of numerous awards, he has held leadership roles in many medical associations. Respected by his colleagues internationally and a dedicated volunteer, he is known for his exemplary commitment to patient care.

The Foundation is extremely proud of Dr. Volpé's achievement and is very grateful for his relentless work as medical adviser to the board.

Dr Volpé, endocrinologue et chercheur réputé à l'échelle internationale, conseiller médical auprès de La Fondation canadienne de la Thyroïde depuis longtemps et président du comité d'examen par les pairs de la Fondation, fut reconnu par la plus grande distinction honorifique de notre pays pour l'oeuvre d'une vie entière. Il fut nommé Officier de l'Ordre du Canada par Son Excellence la très honorable Adrienne Clarkson, Gouverneure générale du Canada, le 17 janvier, 2003.

C'est lui qui, le premier a souligné le rôle de cellules spécialisées du système immunitaire dans les maladies thyroïdiennes. Professeur émérite à l'Université de Toronto et ancien directeur du laboratoire de recherche sur les maladies endocrines de l'hôpital Wellesley, il a agi comme mentor auprès de nombreux jeune scientifiques et médecins du monde entier. Récipiendaire de nombreux prix, il a occupé des fonctions de leadership au sein de nombreuses associations médicales. Bien respecté par ses collègues internationalement et bénévole dévoué, il est reconnu pour son engagement exemplaire à l'égard des soins aux patients.

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Jean-H Dussault 1941-2003

Distinguished Canadian, brilliant researcher, compassionate physician

Dr. Volpé remembers

I am personally very saddened to learn of the death of Dr. Jean Dussault on March 23, 2003, after a courageous battle with cancer. He was one of my very early post-graduate students commencing his research training in my laboratory in 1967. He received his Master's Degree for the work performed in that era. This was to show that the thyroid hormone T3, unlike T4, passed through the animal placenta into the circulation of the foetus and also did so in the human.

Unfortunately, methods for demonstrating T3 were not very accurate in those days and we were insecure about our interpretation of these data. However, Jean commenced his scientific studies in my era through those early experiments and went on to the heights of medical research through his later studies at UCLA and Laval University, where he demonstrated very clearly once again, the passage of T3 into the foetal circulation.

This proved to be of great importance in that he was able to demonstrate cases with congenital hypothyroidism very early in life, and led to the early detection and treatment of this condition thus preventing the onset of the permanent mental and physical damage of cretinism in the child.

I have followed Dr. Dussault's career over the years and was very proud to have this association with him. He was truly a scholar and a gentleman and we were very close friends. When Dr. Jack Puymirat, his colleague at Laval, wrote this memoir, I decided to take advantage of it and present it forthwith.

In Memoriam

Jean Dussault died on March 23, 2003, in his 62nd year of life, thus ending a remarkable career filled with outstanding scientific achievements.

Jean Dussault's personal and scientific accomplishments earned him wide respect and affection. His earliest scientific contribution in the late 1972 was the development of a new blood test for congenital hypothyroidism. He continued with many pioneering and important contributions over the past three decades in-



Dr. Dussault developed a neonatal screening test for congenital hypothyroidism – the heel prick blood test at birth

cluding a neonatal screening program for congenital hypothyroidism and his research on clinical disorders of the thyroid and also on the mode of action of thyroid hormones in the developing brain.

Jean Dussault was born and grew up in Quebec City. He received his bachelor's degree from the University of Montreal in 1960 and his M.D. in 1965 from the University of Laval. He undertook his internship followed by a 2-year residency in medicine at the *Enfant-Jesus Hospital* in Quebec City. His formal research training began in 1967 as a research fellow in Endocrinology under the mentorship of Dr. Robert Volpé at Wellesley Hospital (University of Toronto) and then in the department of Pediatrics and Medicine, UCLA, under the mentorship of Drs. D.A. Fisher and D.H. Salomon. In 1971 he came back to Quebec City and was promoted to assistant professor at Laval University School of Medicine (service of Endocrinology and Metabolism). He worked at the *CHU Laval* where he was an active scientist for 32 years. In 1974, he was made director of the Screening Program for Congenital Hypothyroidism; the Quebec Network for Genetic Disease. In parallel, he established an independent laboratory and resumed his research on thyroid hormone action in the developing brain. Between 1986 and 1996, he was Chief of the Unit of Molecular Medicine Genetics at the *CHUL Research Centre*.

Jean Dussault's contributions to Endocrinology are monumental. With well over 200 publications, he and his colleagues made pioneering contributions in areas ranging from basic mechanisms of thyroid hormone action in the developing brain, to the diagnosis and treatment of thyroid dysfunction. Jean's efforts lead to the development of a new neonatal diag-

nosis test for congenital hypothyroidism, a test currently used worldwide. In 2000, about 150 million newborns were tested for congenital hypothyroidism using this test.

Numerous investigators trained by Jean can now be found in leading endocrine laboratories around the country and, indeed, around the world. Jean was a fine physician and many patients were referred to him at *CHU Laval* from different hospitals. He was always a warm and thoughtful physician for his patients and remained in touch with them over the years. He was also an international expert in the field of thyroid hormones and his opinion was often sought after.

Jean's outstanding accomplishments were recognized by numerous organizations and led to his receiving widespread recognition and awards. Some examples include his nomination for the Nobel Prize of Medicine in 1982 at 42 years of age, the Ross Award in 1976 (American Academy of Pediatrics), the Van Meter-Armour Award in 1980 (American Thyroid Association), Poulenc Santé Pediatric Award in 1987, the Manning award in 1988, the 125th anniversary medal for Canadian Confederation in 1992, the Wallace Robert Guthrie Award in 1999 (International Society for Neonatal Screening). Dr Dussault was appointed a Member of the Order of Canada in 1988 and a Member of the National Order of Québec in 2000.

Despite his many accomplishments and widespread recognition nationally and internationally as a leading scientist who made pioneering contributions in the field of thyroid hormones, Jean remained a modest man. He always declined to apply for a patent for the neonatal blood test for congenital hypothyroidism that he developed because he considered his discovery as being part of the public domain. In remembering Jean Dussault we should focus on his personal example as a physician-scientist who could be intellectually rigorous and highly productive, while at the same time most compassionate and gentle in his manner towards all.

Jack Puymirat, MD, PhD
Director of the Laboratory of Human Genetics
CHU Laval Research Centre,
Sainte-Foy, Québec

The Commemorative Medal for the Golden Jubilee of Her Majesty Queen Elizabeth II

Commemorative medals are struck from time to time to mark special anniversaries and great occasions. In keeping with this tradition, the Golden Jubilee Medal of Queen Elizabeth II commemorates the fiftieth anniversary of Her Majesty's reign as Queen of Canada. This medal is awarded to Canadians who have made a significant contribution to their fellow citizens, their community or to Canada.

We are pleased to announce that both Dr. Robert Volpé, O.C. and Mabel Miller, President of Gander chapter and Chair of the 2002-2003 Nominating Committee, have received this honour.



Hon. Ed Roberts, Lieutenant Governor of Newfoundland and Labrador, presenting the Golden Jubilee Medal of Queen Elizabeth II to Mabel Miller.

Thyroid Foundation of Canada

Presents

Thyroid Update Forum Saturday June 7, 2003

An educational forum for patients and professionals

Where: Holiday Inn Select Airport Toronto
970 Dixon Road, Etobicoke, Ontario

Time: 8:30 AM - 5:00 PM

Registration: \$25.00 (including Continental Breakfast at 8:30 AM)

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Thyroid Federation International

Not all members of the Thyroid Foundation of Canada (TFC) and readers of *thyrobulletin* may be aware that the Foundation is a member of another thyroid organization – Thyroid Federation International (TFI), born in Toronto, Canada, September 1995 in conjunction with the 15th Annual General Meeting of the Foundation and the 11th International Thyroid Congress. The Congress, which is held every five years, gathered over 2000 thyroidologists from around the world. This was the first time it was held in Canada.

On a Sunday morning a large group of interested people met to discuss the possibility of starting an international patient-oriented organization. Representatives from Canada, Germany, England and the United States of America attended the meeting. Diana Abramsky, founder of TFC, gave a moving welcome at this planning meeting for an 'international federation of thyroid foundations', and said, "Just spread the word". Diana, whose life-long dream had been to start such an organization, was the Founder not only of TFC but TFI. Other notables present were Dr. Peter Pfannenstiel of Germany and Dr.

Larry Wood of U.S.A. who presided at the meeting and became the prime mover, organizer and first president of TFI.

Since 1995, TFI has grown to 20 member organizations from 16 countries from Australia to South America. It meets once a year in conjunction with one of the international medical thyroid organizations. It met in Germany, Poland, Greece, Italy, Japan and Sweden. The shared mission is 'Working for the benefit of those affected by thyroid disorders throughout the world'. Each TFI member manages its own program, but gains much by meeting together to share information, ideas and projects. The fellowship is infectious and beyond value.

TFI operates on a shoestring budget, most delegates paying part, if not all, of their expenses. As editor of *ThyroWorld*, TFI's newsletter, I have been privileged to attend most of the meetings and to represent TFC. Great progress has been made in the recognition of TFI's work by the professional community. In Warsaw, TFI was recognized as a satellite organization and in Sweden, Yvonne Andersson was given the opportunity to address the assembly where she made an eloquent plea

for cooperation between professional and patient organizations. At each meeting TFI has a display booth with brochures and information from each country attractively displayed. There are always many visitors, much interest and many questions asked on how to start a patient organization. It is not always easy to do so in other countries. The 2003 meeting will be held in Edinburgh, Scotland in mid-October.

If you are interested in learning more about TFI, copies of *ThyroWorld* can be obtained from: Katherine Keen, Administrative Assistant, Thyroid Federation International, PO Box 1919 Stn Main, Kingston ON K7L 5J7.

June Rose-Beaty
Editor, *ThyroWorld*



www.thyroid-fed.org

Thyroid Foundation of Canada
La Fondation canadienne de la Thyroïde

Founded in/Fondée à Kingston, Ontario, in 1980

Founder

Diana Meltzer Abramsky, CM, BA
(1915 – 2000)

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La Fondation canadienne de la Thyroïde

ISSN 0832-7076 Canadian Publications Mail Product Sales Agreement #139122

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

Deadline for contributions for next issue: June 15, 2003

Le **thyrobulletin** est publié quatre fois par année: la première semaine de mai
(printemps), août (été), novembre (automne) et février (hiver).

La date limite pour les articles pour le prochain numéro: le 15 juin, 2003

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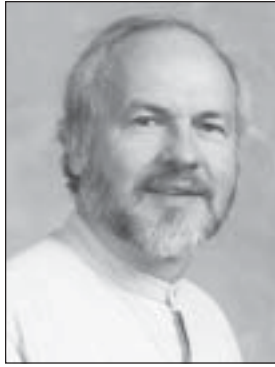
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médicale. Pour questions
touchant les traitements
individuels, veuillez consulter
votre médecin.

President's message

This has been quite a year for the Foundation and me. We have weathered a difficult financial situation and more importantly have launched a campaign to raise funds for our well-being and growth.

The president's challenge was very successful and I would like to report that every member of our board has made a financial contribution to TFC. This underlines the commitment of our board to the organization. Board members contribute their time and energy and back their position with their cheque book. I would like to acknowledge their support and contribution. Thanks.

Our 23rd AGM, postponed until the fall, will be held in conjunction with our medical conference, Thyroid Update Forum. This is a first for the Foundation since 1995. Ted Hawkins was on point for us with this project and has worked very hard to make this event a reality. Our co-chairs are Dr. Robert Volpé OC, and Dr. Irving Rosen. Both have been instrumental in or-



Ed Antosz
National president/Président national

ganizing the conference, recruiting speakers and helping structure this event.

Our AGM will feature several workshops to look at our direction and the governance we require to move in that direction.

Ted Hawkins was instrumental in birthing this conference and his contribution is greatly appreciated. Ted also did a tremendous amount of legwork for TFC

in September by obtaining \$40,000 for the sponsorship of *thyrobulletin* over the next two years. Support has come from Abbott Laboratories Limited, **genzyme** Canada Inc, The Head & Neck Cancer Foundation and Theramed Corporation. Thank you.

I will be stepping down from my position due to personal reasons but will still be involved with TFC in a lower profile position. I hope at a future date to resume a more active role.

This year would not have been as successful were it not for the help of the executive, other members of the board, the chapters, the editorial committee and Ted Hawkins. Katherine Keen and Helen Smith, TFC's office staff, have been tremendously helpful to me. They have worked hard for the organization and their efforts are appreciated.

Thanks to all who have supported me and helped to keep the Foundation going and, more importantly, looking for ways to be bigger and better.

Message du président

Ce fut toute une année pour la Fondation et pour moi. Nous avons surmonté une situation financière difficile et d'encore plus d'importance nous avons lancé une campagne pour ramasser les fonds nécessaires pour notre bien être et notre croissance.

Le défi du président fut couronné de succès et je dois annoncer que chaque membre du conseil a fait une contribution financière à FCT. Ceci souligne l'engagement de notre conseil à l'organisme. Les membres du conseil contribuent leur temps et leurs énergies et ils appuient leur position avec leur chéquier. Je voudrais bien reconnaître leur appui et leur contribution. Merci.

Notre 23ième AGA, est remise à l'automne et prendra place en conjonction avec notre conférence médicale, Thyroid Update Forum. Pour la Fondation ce sera la première fois depuis 1995. Ted Hawkins fut à point avec ce projet et travailla bien fort pour réaliser cet événement. Nos coprésidents sont Dr Robert Volpé, OC, et Dr Irving Rosen. Ils ont organisé la conférence, ont recruté les orateurs et ont aidé à structurer l'événement.

Plusieurs ateliers seront présentés durant notre AGA pour examiner la direction que nous voulons prendre et la gouvernance requise pour se diriger dans cette direction.

Ted Hawkins faisait dérouler cette conférence et sa contribution est très appréciée. Ted a aussi fait un travail remarquable pour la FCT en septembre dernier, en obtenant 40 000\$ pour le parrainage du *thyrobulletin* pour les prochains deux ans. Cet appui nous viens de Abbott Laboratories Limited, **genzyme** Canada Inc, The Head & Neck Cancer Foundation et Theramed Corporation. Merci.

Je démissionne de ma position de président pour raisons personnelles en juin, mais je participerai dans la FCT dans une moindre position. J'espère résumer un rôle plus actif à l'avenir.

Cette dernière année n'aurait pas eu autant de succès sans l'aide du comité exécutif, les autres membres du conseil, les sections, le comité éditorial et Ted Hawkins. Katherine Keen et Helen Smith, le personnel de FCT, m'ont offert énormément d'aide. Ils ont travaillé très fort pour l'organisme et leurs efforts sont appréciés.

Un grand merci à ceux et celles qui m'ont supporté et qui ont aidé à la continuation de la Fondation, et de plus ont cherché des façons de l'agrandir et de l'améliorer.

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

Contributions to:

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Our research dollars at work

Identification of a new cofactor for thyroid hormone receptors A possible advance in thyroid hormone action

Th thyroid hormones are essential to life and have important effects on metabolism, growth and development. More specifically, they control digestion, cardiac rate, body temperature, nervous system, reproduction and weight. All the organs and tissues of our body are composed of cells. Thyroid hormones mediate their actions by binding to receptors (TR: thyroid hormone receptors) mostly present in the cell nucleus. The binding of the hormone to the receptor modifies its effect on target gene expression (activity), which is a finely regulated process.

Abnormalities in the control of gene expression can have profound effects on cell function and can lead to diseases such as cancer. In association with a subset of protein cofactors, TRs provide a high level of control on gene expression. The main interest of our laboratory is the study of the mechanism of action of TRs.

In the last few years, many protein partners for TRs have been described, but there are still some gaps remaining in our understanding of the mechanisms of thyroid hormone action. Our laboratory has identified a new protein partner for TR, which was initially identified as a Ran-binding protein. Ran is best known for controlling the shuttling of proteins in and out of the nucleus.

by
Liette Laflamme, PhD

We have found that our protein can bind the DNA-binding domain of TR without affecting the ability of the receptor to bind target genes. However, this protein seems to negatively influence gene expression. We thus need to find out how and why this happens. We are currently concentrating our efforts on two possible explanations.

Hypothesis 1: The DNA-binding domain of the TR recognized by this protein contains a nuclear exportation se-

quence. By binding to the TR, the protein, in conjunction with Ran, could force the receptor out of the nucleus. As a result, TR would no longer be available to bind target genes; this could thus explain the decrease in gene expression.

Hypothesis 2: Proteins synthesized by the cell have a lifespan dictated by cellular needs. Subsequent protein inactivation is accomplished by proteasomes, which are units of protein degradation. Some recent studies suggest that our protein could be part of the regulatory region of the proteasome, like other TR cofactors (TRIP1, Tat-binding protein-1) that also control gene expression. By this means, this protein could control both gene expressions and TR stability.

The financial support provided by the Thyroid Foundation of Canada has thus permitted the initiation of an interesting research project that will lead to a better understanding of the molecular mechanism by which TR can exert such important and diverse effects throughout our body.

This research was supported by the Thyroid Foundation of Canada Robert Volpé Research Fellowship 2001-2002 and supervised by Marie-France Langlois, MD, FRCPC, CSPQ, Endocrine Division CHUS, Professeur adjoint, Faculté de médecine Université de Sherbrooke.



(L) Liette Laflamme, PhD and
(R) Marie-France Langlois, MD, FRCPC, CSPQ,

Twenty years of funding thyroid research

Since July 1, 1982 the Thyroid Foundation of Canada/La Fondation canadienne de la Thyroïde has supported thyroid disease research with more than three-quarters of a million dollars:

- 47 Summer Student Scholarships \$151,000
- 22 Research Fellowships 595,000
- Wellesley Hospital Research Foundation..... 15,000

- Doctoral award Canadian Institutes of Health Research (CIHR) 12,394
- Total research awards ... **\$773,394**

The money comes from donations and bequests from members and the public and fundraising efforts by chapters across Canada. For many years the Foundation was the only lay organization in the world to fund thyroid disease research.

The Foundation's Peer Review Committee assesses the scholarship and fellowship applications and sends its recommendations to the national board which makes the final decision.

The committee consists of:

- Robert Volpé, OC, MD, Chair, Toronto
- Jody Ginsberg, MD, Edmonton
- Jacques How, MD, Montreal
- Paul Walfish, MD, Toronto

Nos fonds de recherche à l'oeuvre

Identification d'un nouveau cofacteur pour les récepteurs des hormones thyroïdiennes: vers une meilleure compréhension des mécanismes d'action des hormones thyroïdiennes

Les hormones thyroïdiennes sont essentielles à la vie et exercent de nombreux effets sur le métabolisme, la croissance et le développement. De façon plus spécifique, elles régulent la digestion, la fréquence cardiaque, la température corporelle, le système nerveux, le système de reproduction et le poids. L'ensemble des différents tissus ou organes de notre corps est composé de cellules. Les hormones thyroïdiennes exercent leur effets sur le corps en pénétrant les cellules, puis en se liant à des récepteurs (RT; récepteurs thyroïdiens) localisés au niveau du noyau. La liaison de l'hormone au récepteur informe celui-ci sur l'effet qu'il doit exercer sur l'expression (activité) d'un gène cible. Dans cette manière, les hormones thyroïdiennes amènent des modifications dans la composition d'une cellule et régulent finement son fonctionnement.

Tout dérèglement dans les mécanismes de contrôle de l'expression des gènes est susceptible de générer des maladies importantes telles le cancer. Un haut niveau de contrôle est assuré par l'association des RT à d'autres protéines partenaires, modulant ainsi l'action des RT sur les gènes et assurant l'effet final escompté pour le bon fonctionnement de la cellule. Notre laboratoire s'intéresse à l'étude des mécanismes d'action des RT.

Depuis quelques années, plusieurs protéines partenaires des RT ont été

par
Liette Laflamme, PhD

décrites mais plusieurs demeurent encore inconnues à ce jour, ce qui rend notre compréhension des mécanismes de fonctionnement des RT encore incomplète. Nous avons donc identifié une nouvelle protéine partenaire des RT. Celle-ci a initialement été découverte par son association à Ran dont le rôle principal est de réguler le transport des protéines de part et d'autre du noyau. Toutefois, la protéine que nous avons identifiée est différente des autres protéines qui lient Ran et pourrait également avoir d'autres rôles que celui du transport.

Nos travaux ont montré qu'elle possède la capacité de lier le RT dans son domaine de liaison à l'ADN, mais n'empêche pas le récepteur de reconnaître les gènes cibles. Toutefois, elle semble avoir un effet négatif sur l'expression des gènes. Il nous faut donc trouver pourquoi et comment. Nous poursuivons actuellement deux différentes pistes.

Piste 1: La région des RT que lie notre protéine renferme également une séquence d'exportation nucléaire. La protéine pourrait ainsi lier le RT et *via* son interaction avec Ran, chasser le récepteur à l'extérieur du noyau. Ceci empêcherait le récepteur de lier l'ADN

et pourrait expliquer la diminution de l'expression des gènes.

Piste 2: Toute protéine est produite suite à l'expression d'un gène et possède une durée de vie déterminée en fonction des besoins de la cellule. Lorsque la cellule veut inactiver l'action d'une protéine, elle peut choisir de la détruire au moyen de protéasomes, des complexes de dégradation de protéines. Or, certains résultats suggèrent que notre protéine puisse faire partie de la région régulatrice du protéasome, tout comme d'autres protéines partenaires des RT (TRIP1, Tat-binding protein-1) qui contrôlent également l'expression des gènes. Dans cette manière, elle pourrait à la fois contrôler l'expression des gènes et la stabilité des RT.

Le support financier apporté à ce projet par La Fondation canadienne de la Thyroïde aura donc permis d'initier un projet de recherche fort intéressant nous menant vers une meilleure compréhension des mécanismes moléculaires par lesquels les RT peuvent exercer des effets importants et si variés dans le fonctionnement notre corps.

Cette recherche fut appuyée par la bourse de recherche Robert Volpé 2001-2003 de la Fondation canadienne de la Thyroïde sous la direction de Marie-France Langlois, MD, FRCPC, CSPQ, Endocrine Division CHUS, Professeur adjoint, Faculté de médecine, Université de Sherbrooke.

Foundation's mailbox

Just a note regarding a letter published in the newsletter that stated, in part, there wasn't much information pertaining to those of us with hyperthyroidism. I agree with her but also feel that it is impossible to give information relevant to everyone as our degree of illness (if it can be called that) varies.

However, I believe the Foundation does great work in educating the community health field about thyroid disease.

One area that I would like to see more uniform is the information given out at pharmacies – it seems they are all different, as is pharmacists' advice.

Another suggestion is in regard to diet and possible drug reactions to thyroid. For example, caffeine, kelp (sea salt?), anti-depressants. I received pamphlets full of that information when I first joined but ten years later I tend to forget and would

appreciate a reminder to check on these things once in a while.

Thank you and keep up the good work.

Marleen L. Hillstrom

The next issue of thyrobulletin, Summer 2003, Volume 24, No. 2, will contain several articles on hyperthyroidism.

Editor

Complementary and alternative medical therapies for thyroid disorders



John Wojcik, MD, FRCP
University of Western Ontario

The use of complementary and alternative medical therapies has increased dramatically in the last few years.¹ Visits to complementary and alternative practitioners in the United States increased by more than 47% from 1990 to 1997.² Herbal medicine has grown faster than any other alternative treatment method.^{2,3} Contrary to the generally held view that herbal medicines are devoid of adverse effects, many do have adverse effects and can interact with prescription medications.^{4,5} Information in magazines, books, newspapers, the internet, and other sources can be confusing and misleading. The public are often assured that any improvement in their sense of wellbeing when taking a treatment is proof enough that they must have lacked the essential ingredient(s) provided by the therapy. The test of time is considered adequate proof that the alternative medication is effective. The lack of quality control and standardization results in products that don't contain the amounts of medication claimed or contain other contaminants such as pesticides, herbicides, or heavy metals.^{6,7} In alternative medicine, the questions often unanswered are: has the therapy been shown to be significantly more beneficial than placebo for the condition being treated; and have the adverse effects of the therapy, as compared to placebo, been insignificant compared to the benefits?

Prescription medications must undergo extensive trials in which the answers to these questions have to be affirmative before they are allowed on the market. The cost of answering these questions in terms of time and money is considerable

by
John Wojcik, MD, FRCP
Merrill Edmonds, MD,
FRCPC, FACP

and there is little incentive to do so for providers of complementary and alternative therapies since they can market their products as dietary supplements or other non-prescription remedies without this type of evidence. The process of answering these questions usually involves randomized controlled trials (RCTs).⁸ In the RCT individuals with a specific medical condition, for which the new medication is thought to be beneficial, are asked to volunteer for a trial in which they may be given either the medication or a placebo control. The decision as to whether the individual gets the medication or placebo has to be random (eg. flip of a coin) and neither the individual nor the investigator can know whether the medication or placebo is being administered (double blind). Knowledge by either the subject or the investigator as to whether the individual is actually taking the medication can affect the result. An equal number of individuals are randomly allocated to take the medication or placebo. A beneficial placebo response can be seen in zero to almost 100% of individuals. The response rate depends on a number of factors that include patient characteristics, practitioner characteristics, patient-practitioner interactions, the nature of the condition, and the treatment.⁹ For instance placebos have never been reported to cause a new limb to grow in amputees. Any study of a medication claiming to do so would not even have to be placebo controlled. On the other hand a well-designed brand-name placebo, peddled by a skilled salesperson with impressive testimonials, can improve symptoms such as fatigue in most of us. Even in a RCT when the subjects are told the new treatment has not been proven to be effective, may have side effects, and that they have a 50-50 chance of receiving the medication or placebo, 30% of subjects typically experience a beneficial response to the placebo and 10% experience side effects.



Merrill Edmonds, MD, FRCPC, FACP
Professor of Medicine
University of Western Ontario

Some would argue that even if a therapy causes improvement only by its placebo effect the patient still benefits. What is more important, the patient's improvement or the proven effectiveness of a treatment compared to placebo? Besides, some of the benefits patients receive from prescription medications and other therapies that physicians recommend are likely, at least in part, to be due to the placebo effect. Being able to practice the art of good medicine is considered an integral part of being a good doctor. So what is wrong with encouraging the public to use complementary and alternative medicine even if there is no proven benefit over placebo especially if there is no other proven therapy available? Part of our concern is the cost of these therapies. The more spent on unproven therapies the less available for proven therapies or legitimate research. The bigger concern though has to do with safety. Supporters of alternative therapies frequently use the justification that since these agents are "natural", they must be safe. Just look at the periodic table of the elements to see the strength of this argument. This is the basic stuff of which all matter is made, and includes lead, mercury, and plutonium, which are natural but definitely not safe. So natural does NOT mean safe. Specifically looking at safety, we need to ask ourselves if these agents are not only safe over the short term, but safe over the long-term. Fortunately, most alternative remedies are probably safe in the short term or they would not be around for long. The long-term safety of these

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agents, however, is completely unclear. Again, very little research has been done on this, and more disturbing, there is no attempt being made to follow safety. If problems were suspected, it would be near impossible to study them due to the lack of record-keeping (as these products are over-the-counter), the marked inconsistencies between different preparations of the same medication, and the lack of consistent dosing. Not to mention the lack of interest on the part of the manufacturers! Some of these medications may have serious interactions with pre-existing medical conditions or prescription medications that a person is taking.¹⁰ Worse, it is very difficult to get information about potential interactions. The increasing availability of many of these alternative therapies in pharmacies has also given them the appearance of legitimacy, and the tremendous lobbying of groups supporting alternative therapies makes it very difficult for physicians to discourage their use and remind patients of their potential side effects¹¹.

The terms “alternative medicine” and “complementary medicine” are imprecise and inherently misleading. “Alternative medicine” can be loosely described as practices outside of mainstream health care. Any “alternative medicine” by definition lacks evidence of safety and effectiveness. If proven effective and safe it would soon be incorporated into mainstream health care and would no longer be considered “alternative medicine”. “Complementary medicine” is loosely described as a synthesis of standard and alternative methods that uses the best of both. In truth though, there can be no “alternative” to objective evidence of effectiveness and safety. Arnold Relman, MD former editor of *The New England Journal of Medicine*, has reminded us that “there are not two kinds of medicine, one conventional and the other unconventional, that can be practiced jointly in a new kind of ‘integrative medicine.’ Nor, as Andrew Weil and his friends also would have us believe, are there two kinds of thinking, or two ways to find out which treatments work and which do not. In the best kind of medical practice, all proposed treatments must be tested objectively. In the end, there will only be treatments that pass that test and those that do not, those that are proven worthwhile and those that are not.”¹²

Alternative therapies can be grouped into 3 classes:

1. those that are not beneficial but are potentially harmful
2. those that are not beneficial and not harmful
3. those that are beneficial above placebo proven in clinical trials

Most alternative therapies fit class 2 above. These include large doses of vitamins such as C, E, and B complex, antioxidants such as Coenzyme Q10, and minerals such as selenium and zinc. Also included are other therapies such as acupuncture, ayurvedic medicine, clinical ecology, iridology, colonic irrigation, craniosacral therapy, herbalism,^{13,14} (including Chinese herbs except those containing iodide), iridology, naturopathy, orthomolecular therapy, therapeutic touch, yoga, aromatherapy, Reiki, chelation therapy, chiropractic, and homeopathy (see descriptions below). These alternative therapies have no proven specific benefit or harm in individuals with thyroid disorders but are often quite expensive.

Some therapies (Class 1 above) have the potential or have been shown to cause harm to those with thyroid disorders. Class 1 includes the practice of taking large, unregulated doses of the thyroid hormone triiodothyronine, or T3, with inadequate monitoring based only on body temperature. With this therapy, the potential exists for heart attack and death in those with pre-existing heart disease. Readers should exercise extreme caution when considering this type of alternative therapy. Finally, there are no current alternative therapies that fulfil class 3, that is, with proven benefit above placebo. Some therapies have the potential or have been shown to cause harm to those with thyroid disorders and these will be discussed briefly below.

Kelp and Dulse – Kelp and dulse are produced from dried seaweed and contain large amounts of iodide (0.7mg per tablet). Kelp diets have been promoted for weight loss but can cause goitre (enlarged thyroid) and hypothyroidism especially in patients with underlying thyroid disease. Less frequently kelp and dulse can cause hyperthyroidism. In North America there is already sufficient iodide in the diet and supplements are not necessary and can be harmful.

Tyrosine supplements – Tyrosine is an amino acid that combines with iodide to form thyroid hormone. Some suggest that taking extra tyrosine enhances the func-

tion of the thyroid which in turn results in an improvement in general well-being. The thyroid, however, is not limited by its supply of tyrosine and there is no evidence to support the claims that tyrosine supplements help.

Multivitamins – Although there is no proof of benefit, moderate multivitamin supplementation is recommended in patients with severe hyperthyroidism. This recommendation is based on studies that indicate vitamins are utilized and eliminated at a faster than normal rate in hyperthyroid individuals. Although there is no proof of benefit, mainline medicine still recommends supplementation in severe hyperthyroidism because of the evidence of deficiency and because multivitamin preparations are inexpensive and, in moderation, lack harmful side-effects.

Other nutritional supplements – There is no evidence of any benefit for other nutritional supplements such as Brewer’s yeast, essential fatty acids, vitamins A, C, E, Coenzyme Q10, or Zinc.

Raw Thyroid Gland – Raw thyroid gland has been recommended by some practitioners of alternative medicine. The use of raw beef or pig thyroid gland was first reported to improve the symptoms of hypothyroidism more than 100 years ago. It was obviously not a popular method and was soon replaced by tablets that contained extracts of animal thyroids.

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NOTICE TO ALL MEMBERS

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

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.

The discovery of the structure of thyroxine and the subsequent synthesis of pure thyroid hormone made the treatment of hypothyroidism much more predictable and consistent. There is no evidence of any benefit, beyond the effects provided by thyroid hormone, of taking raw animal thyroid gland or thyroid extract.

Common herbal remedies – Most of the common herbal remedies are not specifically recommended for thyroid disorders, nor is there any evidence of benefit.⁵

Shoulder stand (Yoga) – The shoulder stand is purported to send blood to the neck and gently increase pressure on the thyroid in a way that it enhances the function of the thyroid gland. There is no evidence for any benefit from this maneuver which could be dangerous in those with hypertension and other medical disorders.

Horseradish – Horseradish is used herbally as an antiseptic with circulatory and digestive stimulation effects and as a diuretic. It has been recommended for pulmonary and urinary tract infections, urinary stones, and edematous conditions but is not specifically recommended for

the thyroid. In very large amounts, however, it contains a substance that blocks the thyroid and can cause hypothyroidism.

The above is not an exhaustive list of all of the alternative therapies that have been recommended for patients with thyroid disorders. The explosion in the number of available alternative therapies is testimony to the frequency and severity of symptoms such as fatigue, pain, and depression in the general public. It may also in part be due to the ineffectiveness of traditional therapies to improve these symptoms or the inadequate practice of the art of medicine. We can only hope those taking alternative therapies will not do themselves harm in the process and will not waste resources that could otherwise be directed to proven therapies or the development of effective therapies. For more information the reader is referred to the following websites:

Thyroid Foundation of Canada
<http://www.thyroid.ca>

American Thyroid Association
<http://www.thyroid.org/>

Quackwatch
<http://www.quackwatch.com/>

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Monthly Draw

Renew your membership now and become eligible for our monthly draw

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

Our December 2002 winner was:
Mme. Martha Burnett
Vancouver, British Columbia

Our January 2003 winner was:
Gladys Bryant
Stratford, Ontario

Our February 2003 winner was:
Mr. Vital J. Richard
St. Louis de Kent, New Brunswick

our three winners each received the book "*Thyroid Problems A guide for patients*" by Ivy Fettes, PhD, MD, FRCPC

Donations making a difference!

The good work of charitable foundations depends largely on donations, the Thyroid Foundation of Canada being no exception. Our educational material and programs are made possible by donations, large and small, from caring people whose help we acknowledge with thanks. While it is not possible to list here each and every contribution received during the past year, we would like to acknowledge two major donations.

First, cheques totaling \$5,000 were received recently from Nancy and Bill Jordan (long time TFC members) and their sons Alex and Jim Jordan, Bruell Contracting Limited, Toronto. Secondly, Barb and Ron Manor, Gateway Newsstand, Kingston Centre, have sponsored a Nevada ticket outlet during the past year for TFC's Education & Services Fund. To date the proceeds have exceeded \$13,000.

Thank you

Thyrogen™ added to Ontario drug benefits formulary

(Thyrotropin alfa for injection)

genzyme Canada Inc. is pleased to announce that Thyrogen™ will be added to the Ontario Drug Programs Branch Formulary (ODB) effective April 16 under Limited Use code 368 (for use in the monitoring of patients with well-differentiated thyroid cancer). Thyrogen™ is an important advancement in the management of well-differentiated thyroid cancer when used in conjunction with Thyroglobulin (Tg) testing and/or whole body scanning with or without radioiodine imaging. This ODB addition ensures that optimal thyroid cancer management is now available in Ontario.

Reprinted from
Pharmacy Bulletin Board



Letters to the doctor

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

I have had thyroid disease since my late twenties. I was hyperactive, received radioactive iodine and have been hypothyroid since that time. I did have a problem with my eyes at one point in the beginning but after taking the thyroid medication my eyes recovered fully. I am now forty-five. My doctor advised me at the beginning of December 2001 that my blood work readings were out of whack so she decreased my levothyroxine from 0.15 to 0.15 one day and 0.125 the next. I had more blood work done and my medication was decreased to 0.125 daily and there it remains. Later in December I experienced eye irritation and my eyes looked bloodshot. I attended numerous times at both my optometrist and my doctor and then finally an ophthalmologist who just prescribed eye drops but no one could come up with an idea of what was causing the problem.

On Saturday April 27, 2002, I woke up with a splitting headache and my eyes were very swollen, predominately the right eye. I attended a local Urgent Care Clinic and explained we had just done some remodelling, taking out old carpet and replacing it with new. It was thought I might have some allergies to all the renovations. I subsequently visited a physician who was adamant that it was the chemicals in the new carpeting. She advised me to get the carpet steam-cleaned, which I did. The eye problem persisted.

Feeling extremely frustrated I visited my optometrist and she felt that my eye problem might be associated with my thyroid problem and suggested I make an appointment with my doctor, as she was faxing a letter to my doctor advising the doctor of her findings. I made the appointment with my doctor who insisted this was still probably some allergy but she reluctantly agreed to make appointments for me with an allergist, an endocrinologist and an ophthalmologist. I saw the ophthalmologist and he said I had thyroid eye disease and was sending a letter to my doctor. The allergist also said my eye problem was associated with my thy-

roid disease and was sending a letter to my doctor.

I pleaded with my doctor to arrange an appointment with an endocrinologist but she said she was in contact with the endocrinologist and the endocrinologist did not need to see me because her specialty was not with eyes. My doctor suggested I be put on Vioxx for a two-week period. She suggested I then go on prednisone for one to six months and then go to the Ivey Institute in London where aggressive reconstruction of my eye lids etc. would have to be done.

My optometrist also suggested I attend the Ivey Institute for an MRI. She is arranging an appointment with Doctor Nolan there and hopefully I will be able to get in some time in July of this year, which seems a long wait in my condition but probably I am lucky in the timing. The white of the outer corner of my right eye looks like a pinkish red jelly and actually hangs outside above the lower lid. It was suggested by both my doctor and my optometrist to tape my right eye at night because it does not close properly. I have been doing this nightly. I try to keep my eye lubricated throughout the day to avoid the excessive drying. I do ice the swelling periodically.

My question is: Is there any other medication that I could take to alleviate my eye problem before reconstructive surgery? Through my research it appears that prednisone will just mask the problem but not cure it, and of course, I am worried about the side effects of the drug.

I have reviewed your letter carefully. It is quite clear that you do suffer from Graves' ophthalmopathy which has been progressive. From your description I would fear that you do require reconstructive surgery. You cannot continue to take prednisone forever, and I would certainly be interested in hearing about your appointment with Dr. Nolan. Unfortunately the treatment of Graves' ophthalmopathy is less than ideal. I wish you every success in your future efforts to get this condition under control.

My question is what medications should I take or not take. I was diagnosed with thyroid cancer five years ago. My thyroid was removed and I also received radioactive iodine treatment. My cancer had spread to other nodules in my neck. I have been on thyroid medication since then. Should I be taking Sinutab when I have a cold,

or Claritin when my allergies flare up, or Gravol when travelling? I have been taking these drugs when necessary and have felt no ill effects. What about herbal medications like St. John's Wort etc. I would appreciate any information and comments too. I have found *thyrobulletin* an invaluable source of information.

Thank you for your letter regarding your thyroid cancer. You have been taking thyroid medication ever since your thyroid surgery. Since you are taking thyroid replacement therapy, you are free to take Sinutab or Claritin. You are certainly free to eat or drink what you like under those circumstances. The same is true for herbal medicines such as St. John's Wort. 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.

I was given pamphlets by my pharmacist and a friend encouraged me to see an endocrinologist and to contact the Foundation for support. She had thyroid cancer and her daughter-in-law has it now. I had an adenoma and following a biopsy a thyroidectomy was performed about 12 years ago. Two years ago another thyroid uptake test was done and apparently my thyroid regenerated and grew in again. I no longer take thyroxine. I am no longer hypothyroid but I am hyperthyroid now. The endocrinologist has recommended radioactive iodine treatment. At present I am reluctant to treat the thyroid as I do not have the symptoms of either hypo or hyperthyroidism but I do have a disappearing cyst on the pituitary gland. I need more information.

From the information contained in your letter, you may indeed require a dose of radioactive iodine if you are truly hyperthyroid at this time. However, you may wish to seek another opinion as this point is not quite clear to me. However, hyperthyroidism does require treatment and you should certainly seek it.

HEAD&NECK
CANCER FOUNDATION

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

One patient's perspective on Thyrogen scans

Dianne Dodd, PhD, is an historian, a thyroid cancer survivor, a member of the Canadian Thyroid Cancer Support Group (Thry'vors), a member of the Ottawa chapter and the national board of the Thyroid Foundation of Canada. The viewpoints expressed are her own, and not necessarily shared by or reflective of Thry'vor's or the Thyroid Foundation of Canada, nor the manufacturers or marketers of Thyrogen. Other viewpoints are welcome.

by
Dianne Dodd

A new drug, Thyrogen, featured in the last issue of thyrobulletin, has recently been approved for use in Canada. It elevates a thyroid cancer patient's thyroid stimulating hormone (TSH), allowing them to have radioactive iodine scans (in some cases even treatments) without going through the debilitating process of hypothyroidism (withdrawal from thyroid medication). For high risk patients requiring periodic scanning, those patients who cannot become hypothyroid or who have aggressive forms of the disease, Thyrogen improves quality of life throughout treatment and monitoring and can even be a lifesaver. But what about the low or medium risk patients? Do they need to have scans using Thyrogen when their physicians previously recommended none? This question has come up for me, and will no doubt do so for others. Here are some thoughts on the question: "Do I really need one?"

When diagnosed in 1999 with thyroid cancer, I received what was fast becoming the standard treatment for all thyroid cancer patients, even low risk cases. I had a partial, then a completion thyroidectomy, radioactive iodine (RAI) treatment and a diagnostic scan. Compared with previous medical protocols in which lower risk patients were treated with surgery alone, this represented a newer, more aggressive treatment protocol. I was assured this treatment would reduce my risk of recurrence and allow my physicians to follow me with regular thyroglobulin (Tg) blood tests, an effective indicator of recurrence. As a female under the age of 45 at diagnosis, with no distant metastases, relatively small tumour, a clean scan post treatment, and no evidence of elevated Tg, I understood I would not need further scanning and that the risk of my thyroid cancer recurring was quite low.

Now, three years later, with Thyrogen available, I am being offered the option of being scanned again and having my Tg tested with elevated TSH. Not because there is any evidence of recurrence – my Tg has always been undetectable. Why do I suddenly need to be scanned when before this drug was available, I didn't need to be scanned? I am confused! When I was treated I was told that Thyrogen was not as accurate as 'going hypo' for treatment and scans, and that, having had RAI, I could be followed by Tg alone, a simple blood test.

Cancer specialists and pharmaceutical companies are now telling us that scans were not recommended in the past because the horrors of going hypo led most patients to refuse them – an understandable response in my view. Now, with scanning made easier (although certainly not cheaper) they are promoting more scanning, and doctors are beginning to ask for them more routinely. But I'm a sceptical health consumer and I'm not convinced I need this new technology. So, to answer my doubts, the Thyrogen promoters are now questioning the effectiveness of the existing monitoring tools, telling us that the accuracy of Tg readings taken while on hormone replacement medication are not as accurate as they are when a patient is off it. But how much more accurate is it? And, is it really warranted in low risk cases where there is no evidence of recurrence and the risk is already very low?

Weighing the Costs and Benefits

What does this mean for the patient? As a thyroid cancer survivor, I am much more than a cancer statistic, or a tiny piece of a pharmaceutical market. I have a life to live, a family to care for, volunteer and leisure activities to enjoy and other health concerns. Any treatment or monitoring program I accept should take this into account and be assessed not only on medical grounds, but social, economic and psychological. What are the benefits of an additional Thyrogen scan in reduced risk of illness or recurrence and do they warrant the cost and invasiveness?

First, let's consider the practical con-

cerns. Thyrogen costs in the neighbourhood of \$1600. Even for the lucky minority who have adequate third party insurance coverage, it is costly. In my own case, I have 80% coverage, so it will still cost me \$320 for one scan. This is, of course, only the cost to me personally. We all pay for health care – through our taxes, our insurance premiums and even in the smaller pay increases we may get in order to compensate for rising insurance costs. And of course, we all pay the salaries of health care professionals who administer the two injections, the radioactive iodine test dose and the whole body scan. I can't help asking – is a test that will give me 100% assurance that there is no cancer recurrence (when the risk is already low) take priority over treating someone with more pressing medical needs?

Then, there are the psychological aspects. Every form of monitoring has an invasive component to it. Going hypothyroid for a scan is much more invasive than taking Thyrogen. But having a Thyrogen scan is also more invasive than having bloodwork done. It involves four visits to a health care facility/hospital: one for the first injection, then another injection the second day, followed by administration of the RAI diagnostic dose, and finally the whole body scan. If the scan is clean, and the physician decides there is no further follow up needed, GREAT. But what if the results are inconclusive? Indeed, some people have already had clean scans, followed by an elevated Tg. What does that mean? Will the doctors do another treatment (just in case), or just 'watch' it? Watching it, in my experience, means more doctors appointments and more worrying that maybe this time the cancer has 'come back'.

We have some excellent thyroid cancer specialists who are experts in HOW to treat and monitor thyroid cancer. Their knowledge is informed by the latest scientific findings. However their clinical experience is often focussed on the high risk, exceptional cases. While their diligence in treatment and prevention is praiseworthy, there may be times when it is misplaced. Do we need to apply it to the majority of routine, low risk patients who have already received the gold standard of treatment, which is more aggres-

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Comments on 'One patient's perspective on Thyrogen scans'

Ms Dodd raises some valid points. In responding, I do not do so either as an adversary or as a shill of the pharmaceutical industry. I have had the privilege of managing some of my patients with Thyrogen for six years and have participated in several international trials with the drug. This drug is opening a door of opportunity to rethink how we ought to manage and follow up thyroid cancers over the longer term. There are currently working groups in both North America and in Europe engaged in this task. Some preliminary opinions are appearing now and guidelines should be forthcoming. It is very difficult to provide hard evidence on every point of contention in relation to thyroid cancer because it would be necessary to have about 30 years of follow up on a large series to reach conclusions based on outcomes such as recurrence or survival.

For many years the standard of care for thyroid cancer has included life-long follow up. Most guidelines include some follow up I-131 imaging within the first five years or so. Even though we all routinely perform Tg testing on patients who are on thyroid hormone, we know that this has a sensitivity of only about 60% for the detection of occult recurrence. When hypothyroid or stimulated by rTSH the sensitivity rises to nearly 100%. Therefore, in some follow up schemes it is now being suggested that rTSH-stimulated Tg alone without a diagnostic I-131 scan will be adequate follow up in future for many patients. So, in some ways, the follow up may become simpler through the use of

by
Dr. A.A. Driedger

Thyrogen and possible to do in the physician's office.

One of the things that needs to be clarified is what is meant by 'low risk'. To me it means something like a 5% lifetime likelihood of recurrence. It is precisely in the low risk group that one may fall asleep on the job and miss an early recurrence. It is for that reason that an objective test serves the patient better than simple clinical surveillance.

Ms Dodd raises the question of cost and rightly so. We need to balance that against the cost of current practices, which include time lost from unemployment for hypothyroidism as well as the eventual cost of recurrences in about 5% of cases, which if not treated in a timely fashion, will result in some deaths. I don't know that anyone has been able to perform this assessment accurately until now.

Ms Dodd should be made aware that an elevated Tg is always a significant finding and requires aggressive follow up. In my experience with more than 700 cases over 30 years, elevation of Tg always signifies disease. When nothing is found immediately, it becomes a waiting game. In one instance I followed an elevated Tg for 18 years before the metastases became apparent. As with all recurrences of cancer, early therapy is more likely to be successful than if given late.

Ms Dodd is concerned that physicians may be using Thyrogen-based follow up to protect themselves from litigation. I

cannot comment on whether this is so or not in the U.S.A. It is certainly not true in the same way in Canada.

Again, Ms Dodd is correct about the responsibilities of physicians to ask critical questions of the pharmaceutical industry and we do that. At the same time, we are dependent upon the resources of this large industry to continue to develop new and better treatments. I do take exception to her assertion that thyroid cancer is a rare form of the disease: it is now the 8th commonest cancer of women in North America and increasing year by year by about 6%. Further, in men it is a more aggressive disease. The shelf space in my office where I keep the charts of my patients who died of thyroid cancer is filled to a length of three metres.

In summary, the importance of Thyrogen for the practice of thyroid oncology is that its use is associated with a great reduction in the margin of uncertainty that lingers after Tg assays done while on thyroid hormone and sometimes even after an I-131 scan. Whether Ms Dodd chooses to undergo the recommended testing or not will be her decision. If she has the high level of altruism to decide that associated dollars could be better spent on other more important health services and to live comfortably with whatever residual level of uncertainty there may be in her physician's mind about her thyroid cancer status, then she ought to do that.

*A.A. Driedger, MD, PhD, FRCPC, FACP, FCPE
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One patient's . . . continued from page 12

sive than what was used 15 years ago? In the United States, medical litigation is more prevalent than in Canada, but even here we know that medical decisions are sometimes made in anticipation of legal repercussions. For me, I want to know that whether I'm being offered a Thyrogen scan because I really need it, and not because my physician wants to protect him or herself in the unlikely event that I have a recurrence and decide to sue because I wasn't offered the latest highly sensitive technology to detect it.

As well as their doctors, patients have the right and even the responsibility to ask critical questions of the pharmaceutical industry. Developing new drugs like Thyrogen, they have added to the arsenal of medical tools in monitoring thyroid cancer, for which there are many benefits. However, in promoting more routine scanning and Tg testing using the very expensive drug, Thyrogen, are they attempting to expand an already small market? Thyroid cancer, although increasing in incidence is still a fairly rare form of cancer.

Obviously, the decision to have a Thyrogen scan is an individual one. For some, the added assurance of a slightly

more accurate Tg reading and an additional scan may be worth the expense and inconvenience. For others, using this ultra sensitive marker, may not be worth the expense, the inconvenience and worry it may entail if results are inconclusive. If they have already gone through RAI in order to be assured of Tg as a good marker for recurrence and their risk of recurrence is low, shouldn't the effort put into monitoring reflect that? Whatever your choice, make sure your decision is an informed one. Don't be afraid to ask critical questions of your physicians and pharmacists before you go ahead.

Chapter news

Avalon/St. John's



Bea Willis and Kathryn Downton

Avalon Area Chapter meeting was a great success! Amelia Hodder had longed to see the Avalon chapter up and running again as it did many years ago when she was president. Not being able to continue in an executive capacity she called upon the assistance of Nathalie Gifford, TFC National VP Chapter Organization & Development and Mabel Miller, Gander NL, a member of her committee to give a hand. A public education meeting was planned and with lots of publicity it resulted in being an overwhelming success.

On Thursday March 20, 2003, approximately 65 thyroid patients in and around the Avalon Peninsula, including St. John's, were very fortunate in having the opportunity of hearing a renowned thyroid specialist, Dr. David Ingram, speak on *The spectrum of thyroid disease*. Dr. Ingram's talk covered the various conditions that may occur when the thyroid malfunctions, and he answered numerous questions from the audience.

Many thanks to Kathryn Downton and Grace Bavington who have offered to help Amelia in future projects and the formation of an executive. We look forward to hearing from them and wish them well.

Burlington/Hamilton

We hope many people turn out for the chapter events in May and June. Please note the varied locations. In September we are planning a meeting focussing on the diagnosis, treatment and after care of people dealing with thyroid cancer. We

Dr. David Ingram speaking on "The spectrum of thyroid disease"



Dr. David Ingram

hope to have this televised and to reach as many people as we can in the Halton, Hamilton and Niagara districts.

Gander

Gander chapter is currently preparing a large distribution of education materials to the various hospitals, medical clinics and pharmacies within its area. This includes all the towns west and north of Terra Nova National Park as well as Labrador.

On February 14 the draw was held for the beautiful quilt for which we sold tickets. The winner was Ms Marjorie Young of Gander – a wonderful gift for a wonderful lady on Valentine's Day. Many thanks to all who participated by selling and buying tickets.

June is Thyroid Month in Canada. Plans are underway for various activities such as displays at shopping malls and medical centres, a walk-a-thon, etc. Anyone interested in helping out with these activities please call 256-3073 or 256-7687.

Kingston

Phyllis Mackey, a Founding member of TFC, again made a generous donation of \$500 to the chapter, plus \$65 from the sale of 'Avon puppies'. Phyllis, we appreciate your ongoing support. It encourages us to keep working. Thank you.

We regret to announce the death of Joan E. Saunders, a long-time member of the chapter board.

Kitchener/Waterloo

The K-W chapter staffed booths at two Wellness Fairs, a table at the Waterloo Recreation Centre in honour of International Women's Day, and a display at the Wilfred Laurier University Healing Garden Health Fair put on by the Kinesiology and Physical Education departments. We gave assistance and information to two nursing students at Conestoga College in Kitchener for a project on thyroid disease and lent them our copies of Dr. Volpé's videos on hypo and hyperthyroidism. We provided the college library with permanent thyroid reference material.

We extend our sincere sympathy to the family of Hazel Mack of Listowel, who died in her 83rd year. Hazel was the chapter's member-at-large for the Listowel area and she staffed education tables at the hospital in the area north of Kitchener.



Donna Kent, Education Chair
Kitchener/Waterloo

London

This is Healthy Living year and a Healthy Living Fair was held on Saturday February 22, 2003 at the convention Centre, sponsored by the Good Life Fitness Clubs for the benefit of London Health Sciences Centre and St. Joseph's Health Care, London. This was a first for this type of fair and was very well attended by the members from the medical field and the public. There were presentations, talks, videos shown on health issues, prostate cancer, obesity, arthritis to name a few. Booths were set up for asthma, mental health issues, cancer, heart and stroke, with demonstrations of different exercises, diet etc.

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Chapter coming events

Free admission – everyone welcome

Burlington/Hamilton

Location: **NEW! Stoney Creek** – Cardinal Newman High School, lecture hall, main entrance, 127 Gray's Road.

- Tuesday May 13, 2003, 7:00 pm. **Dr. William Harper**, Endocrinologist Hamilton Health Sciences-General Hospital. Topic: *Hypothyroidism*. Following the education meeting the chapter's Annual General Meeting will take place. We are using facilities other than hospitals to alleviate health concerns. Free parking.

Location: **Brantford** – Best Western Brant Park Inn, 19 Holiday Drive

- Tuesday June 3, 2003, 7:00 pm. **Denise O'Hanion. B.Sc.Pharm., Pharmacist**, Dell Pharmacy. Topic: *Ask your pharmacist*.

Location: **NEW! Hamilton** – Spector Auditorium, 44 Frid Street

- September, date & time TBA. **Panel discussion**. Topic *Thyroid cancer*.

For information call: (905) 577-2433 or E-mail: dan.tammy.butt@sympatico.ca.

• 3rd Annual Flower Sale

Location: 33 Alterra Blvd, Ancaster

- Saturday May 24 & Sunday May 25, 2003, 9:00 am to 3:00 pm. held in

conjunction with neighbourhood garage sale.

For information call: (905) 577-2433.

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 May 20, 2003, 7:30 pm. **Dr. Cheryl Clarson**, Paediatric Endocrinologist, Children's Hospital, Western Ontario. Topic: *Thyroid problems from infancy to adolescence!*

- Tuesday September 16, 2003, 7:30 pm. **Dr. Merrill Edmonds**, Endocrinologist, St. Joseph's Health Centre. Topic: *What does the thyroid do?*

For information call (519) 649-1145.

Moncton

An education meeting is planned for May or June 2003. Please call the Helpline: (506) 856-5121 for details of time, date, location and program.

tient, Dr. Phillip Barron on the surgery involved and Maureen Murdock, Clinic Manager, on post-operative management and care. Their presentation was well received. One enthusiastic member called out our Helpline number (613) 729-9089 and said "Don't forget it!". Sadly we said goodbye to Maureen Murdock who is leaving her position at the Civic Campus to take up new responsibilities at the General Hospital. She has been a loyal friend and supporter of the Ottawa chapter for many years. Her farewell performance was superb and she will be greatly missed.

Out of a clear blue sky, it was suddenly raining pennies from heaven. The voice at the other end of the Helpline announced she would like to make a donation to the Ottawa chapter – and not just pennies but \$1,000. We were flabbergasted but delighted and most appreciative. The donor was Debbie Lalonde. Since both she and her mother have thyroid conditions she wanted to give the Ottawa chapter a little boost. Her generous gift represents part of the proceeds from the Arts and Crafts Fair at Stittsville which she organizes every November. Her gift not only boosted our financial stock but also our morale after a difficult year. Thank you, Debbie.

Thunder Bay

Volunteers are needed to assist in chapter activities. If you can help in any way please contact Darlene Ibey, chapter president, (807) 683-5419. The Foundation extends sincere condolences to Darlene Ibey and family upon the death of her father, February, 2003 and to Susan Pagnotta, chapter Past President, upon the death of her father in August 2002.

Chapter news . . . continued from page 14

It was a wonderful opportunity to raise public awareness and inform people that there is a Thyroid Foundation of Canada with a London chapter for public education meetings. We are looking forward to participating another year.

Montreal

In February Dr. François Gilbert, guest speaker, spoke about the detection and treatment of *Thyroid cancer, the benign disease*. Dr Gilbert has been most supportive of the chapter and for that we thank him. Mel Alter, Compounding Pharmacist, was the April speaker, topic: *Thyroid and its environment*, a very informative meeting.

Ottawa

A successful public education meeting was held on February 18 with three speak-

ers giving their viewpoints on thyroid cancer. Dianne Dodd, President of Thy'vors and member of Ottawa chapter spoke from her experience as a pa-



Members of the Ottawa chapter pictured with their benefactor Debbie Lalonde (seated).

Trauma of hypothyroidism in our family

This is the story of how undetected hypothyroidism ruined the life of Kathe, a wonderful young wife and mother – my mother. Looking back over sixty years I am still devastated by the tragedy.

Our father often told us how he met and fell in love with that lively and intelligent girl who could sing like a lark and eventually became our mother. She stole his heart. Alfred dutifully went to her father to ask for the hand of his eldest daughter. The stern father insisted on a month's complete separation. The hopeful young swain was even banned from hanging around his beloved's front door. Grandfather Martin wanted to make sure it really was true love, a necessary foundation for a successful marriage. To young Alfred, that month seemed like an eternity. But all things come to an end. The arrangements for a six month engagement and subsequent marriage went full steam ahead. Kathe wore her engagement ring on the right hand; this same ring would be changed to her left hand at the Lutheran church wedding ceremony.

The dowry had been started in earliest childhood, and added to, piece by finely-stitched piece, over the years. Many linens were beautifully embroidered. It was never a problem deciding what to give a girl child; it was always something for her hope chest. Engagement and wedding showers were unknown.

The first world war marred her early marriage. Mother gave birth to a new baby almost every eighteen months, with a couple of miscarriages in between. In my twenties I upbraided my father for not limiting the number of children. He considered that to be the woman's responsibility. Womens' liberation was a far-off dream in those days.

Mother had to be extremely resourceful to care for her growing family, She made all our clothes, including knitting our long stockings and father's socks. Mostly she had help, but she always cared for the babies herself. She must have been a pretty good nurse.

Throughout my childhood and early adolescence mother overcame several

by
Anna Bill

bouts of illness, during which times she took the opportunity to read her accumulated reading material.

In spite of all the hardships we all grew up healthy. The odd problems, such as my severe rickets, were overcome by cod liver oil emulsion. We thought it was delicious! It was something sweet when sugar was scarce and very expensive. Broadleaf plantain healed septic sores, boils etc. Wild herbs sufficed for many ailments such as chest or abdominal problems.

Schooling was a problem, but I was able to attend a Nurses' Training School in England. There were no tuition fees; we paid by hard work. I loved it in spite of the odd tears.

In 1946 I went home to Germany to do relief work and be with the family for a three-week vacation. I was confused and horrified by the change in our mother. Except for her constant sewing, she just wasn't the same person. She was lethargic and wanted to stay in bed till quite late. A dramatic change had taken place and, to my shame, I must confess that I was quite disgusted. I just didn't understand the reason.

Once, when my sister Gretel, her small son and I had gone into Cologne, we returned to find the house ice-cold. Horrified and angry, I asked my mother why the house was so cold. Mother said the fire went out in both stoves, the beautiful kitchen range and the living room stove (something like a Quebec heater). There was plenty of wood and brown coal in the house. Mother declared that she didn't know how to put coal or wood on the fire. I'm ashamed to admit that I was really angry. "Mother" I declared, "this stove and kitchen range were part of your dowry". I just couldn't understand.

Mother hated to be left alone and we spent a great deal of time talking privately. During one of our private chats she told me of an incident, which even now, in January, 2003, reduces me to tears. I can barely control myself when I

remember mother's tears on telling me of that painful fact.

When our brother Fred was killed early in the war, faraway relatives on my fathers' side sent sympathy letters addressed to our father – not a word to our poor mother. For the latter years of his life, Father portrayed Mother as lazy and dull-witted – perhaps these relatives thought she was incapable of understanding, but this thoughtless act was extremely hurtful.

It was not until I was diagnosed with hypothyroidism in the early sixties that I realized that it was hypothyroidism that ruined mother's life, even though no test was ever done and she never received treatment. It may seem incredible, but in over five years of different kinds of nursing training, hypothyroidism was never mentioned. I was familiar with goitre, a large swelling of the throat caused by disease of the thyroid gland. The problem was noticeable on the chronic wards in my large training school, but the subject never came up in our medical lectures.

I was much luckier than mother, although my experience has not been without problems. In the early sixties, just before we embarked on the building of the nursing home in Puslinch, I went to the doctor for a thorough checkup. I wasn't exactly feeling ill, but I realized how tired I was when I struggled to carry two pails of water up the hill for our geese and ducks.

Within a few days, the doctor called and instructed me to get into the office right away. I was suffering from severe hypothyroidism and was prescribed medication that made me feel like a whole new person within just two days. I was more or less on an even keel for two or three years, but then I sensed that something was wrong and asked for another blood test. The doctor switched me from the natural to synthetic medication and the problem was solved. Things went well until I underwent gall bladder surgery. Once more I realized that something was not right. Blood work revealed that I needed a higher dosage, which made me feel much better.

continued on page 18

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.

OFFICERS OF THE FOUNDATION:

President: Ted Hawkins, Toronto, ON

Vice-Presidents (four):

- Publicity & Fund Raising: Gary Winkelman, Vancouver BC
- Chapter Organization & 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

FALL
2003

Due to
SARS
the 23rd AGM
and the
THYROID
UPDATE
FORUM
have been
postponed
till the fall.

Check with our
website
for details.
www.thyroid.ca
as well as our
next issue of
thyrobulletin

Ed Antosz, President

Call our Helplines

for thyroid disease information

In my capacity as Vice-President Education & Research for many years, I have realized that the Helplines many of our chapters provide are a very important aspect of our outreach to people suffering from thyroid disease. The willingness of our Helpline volunteers to spend as much time as is necessary to listen to people with difficulties and to follow-up by sending some of our Health Guides and educational material helps patients better understand their condition. I am very aware of the response from callers having volunteered in this capacity.

Trauma . . . continued from page 16

Then, just a few years ago, I could not understand why I was always feeling so cold. My new doctor ordered tests that revealed very low thyroid levels, but refused to increase the dosage on the grounds that it might prove dangerous. So I changed doctors, and demanded to see an endocrinologist, who increased my dosage. Once more I felt much better within just two days. One year later, tests revealed that my dosage could be lowered.

The iodization of salt was the first important step towards the prevention of some thyroid problems. However, hypothyroidism still goes undiagnosed far too often for far too long. Once diagnosed, regular testing is needed to ensure the correct dosage. Only you know how you feel. If you do not feel right, request a blood test to ensure that the dosage you are taking is still right for you.

Anna Bill is a member of the Kitchener/Waterloo Chapter. During the second world war she, along with other people of German or Austrian birth living in England, was interned on the Isle of Man. In 1998 she published a small booklet - Internment of Women on The Isle of Man. Anna recently moved to a retirement home in Elmira.

by
Lottie Garfield

For many years Laura Mandryk, Education Chairperson Toronto chapter, has managed the Helpline responding to approximately 500 callers per year. Often they become members, make donations or become volunteers. The Foundation's Helpline volunteers are important and appreciated. Thank you for an important contribution to the Foundation that ben-

efits many thyroid disease sufferers. Many callers acknowledge and appreciate this response as expressed in the message below:

Laura:

This big thank you is a long time coming. What an incredibly caring listener you are. You did so much to lift my spirits and encourage me to delve into the data that is available. If I can be a volunteer in any way, please let me know. Thank you! Thank you!"

For Helplines see back cover of *thyrobulletin*.

"Greatness Challenge" Golf Tournament

Tuesday, June 3, 2003

(Deer Creek Golf Club, Ajax, Ontario)

Sponsored by:

The Head & Neck
Cancer Foundation

Fundraising for:

Head & Neck Cancer Scholarships &
Thyroid Foundation of Canada
Education Fund

Tee off time:

1:00 pm

Registration fee:

\$275 per golfer

Information:

Mark Daniels
Executive Director
The Head & Neck Cancer Foundation
2345 Yonge Street, Suite 700
Toronto ON M4P 2E5

Tel: 1-416-324-8178 Ext. 228

E-mail: mdaniels@dancap.com

www.headandneckcanada.com

Opportunities for giving

The Thyroid Foundation of Canada office requires a new computer to replace outdated technology. We need your donations in



order to provide a more efficient mechanism to inform our members of current issues related to thyroid disease. Our goal is to raise \$3,500 by June 30th, 2003.

Hypothyroidism, hyperthyroidism and thyroid cancer can have serious health consequences for people affected with these disorders. Your donation will allow us to increase the role of the Thyroid Foundation of Canada as a source of support and accurate information for individuals affected by thyroid disease, and their families.

To kick off the campaign I have contributed \$250.00, a pledge that is being matched by our national president, Ed Antosz.

Gary Winkelman, Vice President
Publicity & Fundraising

The national office of the
Thyroid Foundation of Canada
has relocated to
797 Princess Street Suite 304
Kingston ON K7L 1G1

Mailing address, telephone
numbers, fax number & website
remain the same.

Thyroid Foundation of Canada
PO Box 1919 Stn Main
Kingston ON K7L 5J7

Tel: (613) 544-8364
1-800-267-8822

Fax: (613) 544-9731

Website: www.thyroid.ca

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: _____

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

Chapter & Area Contacts/Liaisons pour les sections et districts

BRITISH COLUMBIA/COLOMBIE-BRITANNIQUE

Cowichan (250) 245-4041
Vancouver (604) 266-0700

ALBERTA

Calgary (403) 271-7811
Edmonton (780) 467-7962

SASKATCHEWAN

Saskatoon (306) 382-1492
Regina * (306) 789-9383

MANITOBA

Winnipeg (204) 489-8749

QUEBEC/QUÉBEC

Montréal (514) 482-5266

NEW BRUNSWICK/NOUVEAU BRUNSWICK

Moncton (506) 856-5121
Saint John (506) 633-5920

* Area Contact/Contact régionaux

NOVA SCOTIA/NOUVELLE ÉCOSSE

Halifax (902) 477-6606

PRINCE EDWARD ISLAND/ÎLE-DU-PRINCE ÉDOUARD

Charlottetown (902) 566-1259

NEWFOUNDLAND/TERRE NEUVE

Avalon/ St. John's (709) 739-0757
Gander (709) 256-3073
Marystown (709) 279-2499

ONTARIO

Burlington/Hamilton (905) 304-1464
Kingston (613) 389-3691
Kitchener/Waterloo (519) 884-6423
London (519) 649-5478
Ottawa (613) 729-9089
Petawawa/Pembroke (613) 732-1416
Sudbury (705) 983-2982
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
La Fondation canadienne de la Thyroïde
PO BOX/CP 1919 STN MAIN
KINGSTON ON K7L 5J7



Awareness • Support • Research



Éclaircissement • Soutien • Recherche