



Thyroid Foundation of Canada

thyrobulletin

La Fondation canadienne de la Thyroïde

Volume 24, No. 4

Winter 2004



My Thyroid Cancer Journey

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Report of Thyroid Update Forum



Dagmar
Van Beselaere,
member Ottawa
Area Chapter

by /par
Dagmar Van Beselaere

On Saturday, November 1, 2003 as part of the 23rd AGM week-end activities, the Thyroid Foundation of Canada sponsored top researchers, scientists and medical doctors to gather in Toronto to update the public in a forum on thyroid disease. The day long forum was packed full of new and relevant information in a very patient oriented manner.

The morning was devoted to increasing understanding of thyroid cancer, the incidence of which is the fastest growing cancer in Canada. The morning started with a panel of patients expressing their needs in dealing with this illness. This set the tone for the rest of the morning during which presentations were made, not only to medical colleagues, but also to thyroid patients in an understandable manner. It started with a presentation on Cytopathology by Dr. Scott Boerner who showed how fine needle aspiration (FNA)

is done and how the results are interpreted to indicate malignancy/no malignancy. Dr. Marsha Werb talked about the process that a physician goes through to determine a patient's risk of having thyroid cancer, i.e. how a doctor reaches such a diagnosis.

The treatment of thyroid cancer requires surgery, usually the complete removal of the thyroid gland. Two doctors, Dr. Roger Tabah and Dr. Ralph Gilbert, addressed this issue, often with slides showing the actual surgery. To complete the destruction of the thyroid gland, radioactive iodine is usually needed as a final step and Dr. Albert Dreidger spoke about this, showing slides of the radioactive iodine attack on residual cancer cells.

The afternoon was devoted to a sampling of the many other thyroid disorders. Dr. Donald Morrish talked about radiation and Graves' disease, giving a historical perspective on the treatment of this disorder and the newest research on the possible effects of radiation on the illness. Dr. Jay Silverberg addressed the issue of hypothyroidism, again reviewing some of the more recent research which indicates that patients with borderline hypothyroid-

ism seemed to feel better with treatment and that the band of TSH levels for optimal "feeling better" patient reaction is much narrower than previously thought. It should fall between 0.3 to 3.5 milliunits/L. Dr. John Chan explored the relationship between thyroid disease and diabetes, both of which are autoimmune disorders.

After a short break, Dr. James Oestreicher showed how reconstructive surgery can return eyes to near normal after the devastating effects of thyroid eye disease. Dr. Ivy Fettes spoke about the importance of controlling thyroid levels during pregnancy to avoid damage to the foetus. Last, but not least, Dr. Arnold Bayley discussed the effects thyroid disorders can have on bone maintenance and their influence on the development of osteoporosis.

Through the sponsorship of the Thyroid Foundation of Canada, the day was filled with information, some already known but brought to the awareness of thyroid patients with doctors translating the medical shorthand they would use with colleagues so that patients were able to understand, as well as some of the most recent research results. At the end of the day thyroid patients left exhausted with the volume of information absorbed and incredibly better informed about their illness.

Forum mis à jour thyroïde

Le 1^{er} novembre, 2003 La Fondation canadienne de la Thyroïde a commandité un rassemblement à Toronto d'importants chercheurs, scientifiques et médecins pour mettre le public à jour durant un forum sur les affections thyroïdiennes. Le forum a duré toute une journée et était rempli de nouveaux et importants renseignements d'une façon orientée aux patients.

L'avant-midi était dévoué à l'accroissement de discernement du cancer thyroïdien, l'incidence duquel est le plus progressif au Canada. L'avant-midi commençait avec un panneau de patients

qui exprimaient leurs besoins en faisant face à cette maladie.

Ceci a fixé le ton pour le restant de l'avant-midi durant laquelle des présentations étaient données, non seulement aux collègues médicaux mais aussi aux patients thyroïdiens dans une manière compréhensible. On commençait avec une présentation sur la Cytobiologie par le Dr Scott Boerner qui montrait comment une biopsie à l'aiguille fine (BAF) est accomplie et comment les résultats sont interprétés pour indiquer malin/non malin. La Dr Marsha Werb parlait du processus qu'un physicien emploie pour déterminer le risque au patient d'avoir un

cancer thyroïdien, c à d, comment il arrive à ce diagnostic.

Le traitement du cancer thyroïdien nécessite la chirurgie, d'habitude l'enlèvement complet de la glande thyroïde. Les deux docteurs, Roger Tabah et Ralph Gilbert adressaient ce sujet, souvent avec illustrations de la chirurgie actuelle. Pour compléter la destruction de la glande thyroïde, l'iode radioactive est habituellement nécessaire et le Dr Albert Dreidger discourait sur ceci avec illustration de l'attaque d'iode radioactive sur les cellules cancéreuses résidues.

suite à la page 5

**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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Legal Adviser – *Cunningham, Swan, Carty, Little & Bonham LLP*

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

Thyroid Foundation of Canada is a registered charity
number 11926 4422 RR0001.

La Fondation canadienne de la Thyroïde est un organisme de
bienfaisance enregistré numéro 11926 4422 RR0001.



Thyroid Foundation of Canada

thyrobulletin

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: March 15, 2004

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 mars, 2004

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Important Notice:

The information contained within is for general information only and consequently cannot be considered as medical advice to any person. For individual treatment or diagnosis consult your health care professional.

Avis Important:

Les renseignements contenus à l'intérieur sont à titre d'information générale et conséquemment personne ne doit les considérer comme conseils médicaux. Pour traitement ou diagnostic individuel veuillez consulter votre médecin.

L'après-midi était dévoué à des exemples d'un grand nombre d'affections thyroïdiennes. Le Dr Donald Morrish articulait de la radiation et la maladie Graves, donnant une perspective historique sur le traitement de cette maladie et des plus nouvelles recherches sur les effets possibles de la radiation sur la maladie. Le Dr Jay Silverberg adressait le sujet de l'hypothyroïdie, encore en examinant quelques-unes des plus nouvelles recherches qui indiquent que les patients avec un cas limite d'hypothyroïdie se semblent « sentir mieux » avec traitement et que la bande du niveau TSH pour une réaction idéale « sent mieux » du patient est bien plus étroite que l'on pensait auparavant et devrait tomber entre 0,3 et 3,5 milliunités/L. Le Dr John Chan explorait les relations entre les affections thyroïdiennes et la diabète, qui sont tous deux des affections auto-immunes.

Après une courte pause, le Dr James Oestreicher démontrait comment la chirurgie reconstructrice peut normaliser les yeux après les effets ravageant de la maladie thyroïdienne des yeux.

La Dr Ivy Fettes expliquait l'importance de contrôler les niveaux thyroïdiens durant la grossesse pour empêcher d'endommager le fœtus. Le Dr Arnold Bayley terminait la journée en discutant les effets des affections thyroïdiennes peuvent avoir sur le maintien des os et leur influence sur le développement de l'ostéoporose.

La journée était saturée de renseignements, quelques-uns déjà connus mais rappelés à la conscience des patients thyroïdiens. Les médecins ont traduit le « grec » médical qu'ils utiliseraient avec leurs collègues enfin que les patients puissent comprendre les renseignements ainsi que les toutes nouvelles recherches sur les affections thyroïdiennes. A la fin de la journée, par le commanditaire de La Fondation canadienne de la Thyroïde, les patients thyroïdiens départaient épuisés avec le volume de renseignements et incroyablement plus informés de leur maladie.



Monthly Draw

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

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

September 2003 winner

Mrs. Helene Calvert
Ottawa, Ontario

who received a copy of
"Thyroid Problems; a guide for patients"
by Dr. Ivy Fettes

October 2003 winner

Ms. Eva Reti
Whitby, Ontario

who received a copy of
"Thyroid Problems; a guide for patients"
by Dr. Ivy Fettes

November 2003 winner

Mrs. Jewel Comstock
Rosebud, Alberta

who received a copy of
"Your Thyroid: a home reference"
by Dr. L. Wood

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.



Jack Tarantello CGA
Former TFC Accountant

It is with great sadness that the Foundation announces the untimely death of the Foundation's long-time accountant Jack Tarantello, who died peacefully from leukemia at the Kingston General Hospital on Tuesday, December 2nd, 2003.

Jack had been a long-time supporter of the Foundation. In its early days, he was recruited as the Foundation's second treasurer and was a great support to Diana Abramsky in assisting with accounting details on some of her early projects. In 1990, the Foundation received Trillium Funding for contractual accounting services and Jack was hired for this position. For over thirteen years he gave volunteer service above and beyond the paid duties and responsibilities of this position and was of tremendous assistance to the national office staff, national treasurers and auditors during this time. The reliability of TFC's financial records and monthly statements was due to Jack's expertise and dedication to the Foundation.

Jack will be missed by his daughter, his grandchildren, great granddaughter, sisters and brother, as well as his many friends in the accounting community, in Kingston and in the Foundation.



A brief history of the thyroid

Reprinted with permission from *Thyroid Problems: A guide for patients* by Dr. Ivy Fettes.



Dr. Ivy Fettes

by
Dr. Ivy Fettes

Paracelsus (1493-1541) described endemic cretinism in children – a mental deficiency due to severe thyroid hormone deficiency from lack of iodine in the diet.

Thomas Wharton (1614-1673) was the first to describe the ductless glands (now called endocrine glands) and to specifically name the thyroid gland. In 1661 Neils Stensen made the clear distinction between the ductless (endocrine) glands and the lymph nodes, which are sometimes called glands, although they are not part of the endocrine glandular system.

The purpose of the thyroid gland remained unknown in the seventeenth century. Wharton thought it might be present to round out and beautify the neck. Such was the state of medicine at the time.

In the nineteenth century, Robert Graves (1796-1853) gave an excellent description of a combination of thyroid enlargement, eyeball “enlargement,” and a variety of signs and symptoms that we recognize today as characteristic of an overactive thyroid gland (hyperthyroidism). Graves attributed the clinical disorder to the thyroid and henceforth the most common form of hyperthyroidism, which is due to an autoimmune disorder, is called Graves’ disease.

*The term “hormone” was first coined in about 1902 and comes from the Greek word *hormaino*, which means “to stir into action.” Ernest Starling developed the concept of hormones being chemical messengers that are secreted into the bloodstream from endocrine glands.*

Sir William Gull (1816-1890) was the first to describe the adult “cretinoid state” (myxedema or hypothyroidism). The disease had long been recognized in children, but he was the first to recognize it in an adult. Gull had a major interest in neurologic disease and thought myxedema was a disorder of the nervous system. He was, of course, only partially correct.

The late nineteenth century and the twentieth century were marked by major leaps forward in our understanding of the thyroid gland. George Murray deduced that myxedema was due to lack of a particular substance in the body and decided that it was a rational approach to make up that deficiency. He first injected thyroid extract into patients in 1891 and thereby became a pioneer of thyroid replacement therapy.

The most common cause of hypothyroidism is recognized to be due to an autoimmune chronic thyroiditis. The condition was described by Hakuru Hashimoto in 1912 and bears his name (Hashimoto’s thyroiditis).

One of the major events to facilitate our understanding of the thyroid in the twentieth century was the radioimmunoassay technique by Rosalyn Yalow and Solomon Berson in the 1960s. The ability to detect minute amounts of thyroid hormones in the blood enables doctors to detect an excess or deficiency of the hormones. These measurements have become more and more sensitive and are considered standard procedure in making the diagnosis of hyperthyroidism and hypothyroidism.

In the 1970s a pituitary hormone called thyrotropin or thyroid stimulating hormone (TSH) and a hypothalamic hormone called thyrotropin releasing hormone (TRH) were extracted from brain tissue. This enabled scientists to begin to understand the complex interactions between the brain and the thyroid. Research has demonstrated a hierarchical system of stimulation from the hypothalamus to the pituitary and then to the thyroid, which in turn exerts negative feedback on the pituitary and hypothalamus.

continued on page 7

Enlargements of the thyroid, producing a swelling in the neck, are called goitres and have been recognized since ancient times. The Greeks apparently attributed goitres to the type of water people drank. They were at least partly correct because we know that iodine deficiency in the diet predisposes people to the development of goitres, and iodine is frequently found dissolved in water. It has been claimed that seaweed, which contains iodine, was used in treating goitres in ancient China. (The addition of iodized salt to our diets in the last fifty years has resulted in a dramatic decrease in the prevalence of goitre.)

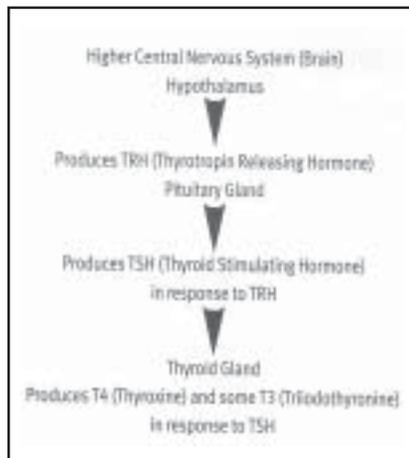
Our understanding of the role of the thyroid gland has evolved over many thousands of years. Hippocrates (460-370 B.C.) is called the “father of medicine” and many medical students throughout the world take the “Hippocratic Oath” at graduation. Hippocrates vastly expanded the art of studying the patient by urging physicians to check the person’s appearance, temperature, respiration and pulse. This facilitated our knowledge of anatomy, physiology, and internal medicine and remains a foundation in medical practice. Hippocrates is considered to have first recognized endocrinology because he described concepts of “too much” or “too little” as a cause of disease.

It was the great physician Galen (130-200 A.D.) who described the anatomical location of the thyroid gland. Much later,

A brief history . . . continued from page 6

“Negative” feedback means that high levels turn off the stimulation and low levels turn on the stimulation. (Just like a thermostat responds to high temperatures by turning off a furnace and to low temperatures by turning it on.)

Axis of Regulation of Thyroid Hormones



Note 1: If too much T4 and T3 are present in the body, then TSH will be turned off (this is called negative feedback).

Note 2: If too little T4 and T3 are present in the body, then TSH will increase to try and drive the thyroid to produce more hormone.

With the rapid evolution of molecular biological techniques in the 1970s, '80s and '90s we have developed a more comprehensive knowledge base of how thyroid hormones exert their multiple and diverse effects. Worldwide there are thousands of thyroid researchers contributing to this effort. We continue to learn and develop more effective means of diagnosing and treating thyroid disease.

Ivy Fettes, PhD, MD, FRCPC, is an Associate Professor in the Department of Medicine, University of Toronto, and an Endocrinologist at Sunnybrook and Women's College Health Sciences Centre, Toronto. Her book is published by Prospero Books, 2001, Toronto.



Letters to the doctor

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

I have been feeling fatigued for many years. I also complain of constipation, lethargy, inability to concentrate and weight gain. I have seen several doctors including an endocrinologist; they have tested my thyroid with blood tests on many occasions. The blood tests always come back completely normal. Yet, I have been reading that these tests are not accurate and that measurements of body temperature are more accurate. Moreover, I understand I should be taking thyroid medication for these symptoms despite normal thyroid function tests.

Actually the routine blood tests for thyroid function are extremely accurate and precise. Moreover, the blood test for thyroid stimulating hormone (TSH) (which is the pituitary hormone that stimulates the thyroid gland even more when it is failing) is extremely accurate. It is the first test to rise when thyroid function is at all low. Indeed, it will go up even before the thyroid hormone levels are detectably lower. This is a category termed "compensated" hypothyroidism. In that state, the thyroid hormone levels are still normal, the patient still feels normal but the TSH is already an indicator that the thyroid gland itself is in trouble. In your case, with a normal TSH, hypothyroidism is completely ruled out.

*It is important to remember that many other conditions can mimic hypothyroidism, most particularly chronic anxiety, depression and stress. Some psychiatrists use T3 (Cytomel, triiodothyronine) but usually **not** thyroxine, with antidepressants. How useful this combination is, remains to be proven.*

It is true, however, that such people who do not have thyroid disease can "benefit" from taking thyroid medication. The reason they are benefitting is that the thyroid medication is a "placebo". The drug itself has no intrinsic benefit to them,

but if people think it is going to help them, then it does. It is like fooling yourself by taking a pill that looks identical but is completely inert. If we convince ourselves that there is some good in it, then we feel much better. Sometimes this placebo effect is truly remarkable and long lasting. More often, however, it lasts for only a short time and disappears. Taking thyroxine when you do not need it, is also of some danger and cannot be encouraged.

Finally, skin temperatures are of no value in diagnosing hypothyroidism despite assertions to the contrary by some. It has been clearly proven they are totally misleading and really useless. While it is true that patients with hypothyroidism do have cool skin, so do people with many other conditions. These include people with poor blood supply, severe stress, anemia and others.

Does a person's age affect the recovery rate from thyroid disease or the amount of supplemental thyroid medication needed? What is considered a "normal range" for thyroid stimulating hormone (TSH), and total serum triiodothyronine (T3 radioimmunoassay (RIA) readings?

Certainly age will affect the recovery rate from thyroid disease, both hyperthyroidism and hypothyroidism. The older the person, the slower the recovery rate and indeed with hypothyroidism, it is necessary to be extremely careful in older people about increasing the dosage of thyroxine.

The normal range for TSH depends on the type of assay utilized. Currently with the sensitive assays now available, the usual normal range is between 0.3 and 3.5 milliunits/L. For the total serum triiodothyronine (T3RAI) once again assays vary a little bit from laboratory to laboratory but the average range is 1.2 to 3.4 nmol/L.

HEAD&NECK
CANCER FOUNDATION

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

Chapter news

Burlington/Hamilton

On November 4, in Burlington, Dr. Sarah Capes gave an excellent presentation on Graves' disease. We are looking forward to more talks by Dr. Capes.

Kitchener/Waterloo

Kitchener/Waterloo area chapter is in the happy position of having been offered a meeting room free of charge. It is in the downtown area, making it easier for those who use the buses. Last spring, at the Women's Day Health Fair, Cassandra Howarth chapter president, was introduced to Anne Celestine, Health Coordinator from the Kitchener Public Library, who was setting up a health link on their computer site, a new Health Information Section in the library, and a series of special talks on Women's Health issues. Anne asked if we could help by being involved in her program. Needless to say she did not need to ask us twice. We are saving \$25 per meeting. We donated one of our books to be used as a reference book in their new health section, and put the chapter's name inside.

The first meeting at the new location was last October with Dr. Cameron Purdon conducting an open forum of questions and answers. These forums are very well received and we had lots of new patients in attendance - more than usual. The meeting night has been changed from Tuesday to Wednesday to see if that will also improve attendance.

To look at the information the library has posted for the chapter, see www.kpl.org. Their e-mail reference is askus@kpl.org.

Sudbury

Lois Lawrence, President of the Sudbury area chapter, forwarded the happy news that Sudbury now has its first ever endocrinologist, Dr. B. Varghese, MD, MRCP (UK) FRCPC. Just a reminder that if you wish to make an appointment with Dr. Varghese it is necessary to be referred by your family physician.

Toronto

On Friday and Saturday, January 15 and 16, the Toronto chapter participated in the 2004 Women's Health Matters Forum and Expo. A booth was set up, the Foundation's literature was distributed and Toronto chapter volunteers talked to many individuals and representatives of other health organizations. On Saturday, at 12:30 pm, Dr. Ivy Fettes, of Sunnybrook and Women's College Health Sciences Centre, a frequent speaker at Thyroid Foundation of Canada events, gave a very informative talk on **Thyroid disease in women** as part of the Forum speakers series. The Women's Health Matters Forum and Expo is a yearly event that draws approximately 10,000 visitors from the Toronto area and beyond.

For educational literature about thyroid disease call our Helpline: 416-398-6184.

Volunteers wanted

Hospital for Sick Children, Toronto

Are you pregnant and being treated for a thyroid problem?

A Thyroid in Pregnancy Study is being conducted at the Hospital for Sick Children in Toronto. The study is evaluating the vision and neurodevelopment of babies whose mothers were hypothyroid or hyperthyroid during their pregnancy. We are looking for women who:

- are pregnant or recently delivered
- had no other illness
- can read English

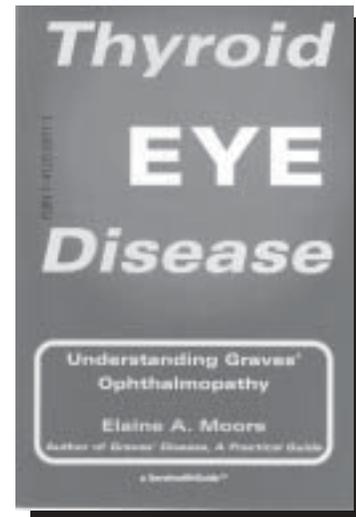
Parking and transportation costs will be provided.

If you are interested and would like more information, please contact:
Laura Kenton or Lara Rosenberg at: 416-813-8285

Hot off the press!

Thyroid Eye Disease

Understanding Graves' Ophthalmopathy



This comprehensive book by Elaine A. Moore, author of *Graves' Disease, A Practical Guide*, is written in plain language for patients with Thyroid Eye Disease. It describes all facets of thyroid eye disease including:

- genetic, environmental and lifestyle factors that contribute to understanding Graves' Ophthalmology (GO)
- signs, symptoms
- diagnostic tests
- risk factors
- complications
- psychosocial issue of living with GO

Elaine is a Medical Technologist, MT (ASCP), with more than 30 years experience working in hospital laboratories. She is the author of numerous books. Visit Elaine at her website at http://daisyelaine_co.tripod.com/gravesdisease.

Published in Canada in 2003 by SarahealthPress, a Division of Sarahealth Inc. ISBN 1-4120-0911-1. This paperback book has 185 pages, including index, and sells for \$24.95 Cdn, \$19.50 US.

For more information visit:
www.thyroid-eye-disease.com

Chapter coming events

Free admission – everyone welcome.
Please mark your calendars

Burlington/Hamilton

- Location: Burlington Art Centre, Shoreline Room, 1333 Lakeshore Road, Burlington. Tuesday, April 13, 2004, 6:30 pm. Member social and annual general meeting. Displays, meet other members, learn about programs, resources of Foundation.
- Location: Hamilton, in partnership with St. Joseph's Healthcare, Healthstyles/Spring Series 2004. June 2004. Date & speaker: TBA. Topic: *Hypothyroidism*.
- Location: TBA. In partnership with Halton HealthCare, October 2004. Date & speaker TBA. Displays and refreshments 6:30 Topic: *Hypothyroidism*.
- Location: Burlington Art Centre, Shoreline Room, 1333 Lakeshore Road, Burlington. Tuesday, November 9, 2004, 7:00 pm. Speaker TBA. Topic: *Thyroid disease and the family*.
- **Mayor's Walk for Volunteerism** – Hamilton's Bayfront Park Trail in May (date TBA). Support the Thyroid Foundation programs by participating in the Mayor's Walk.
- **4th Annual Spring Flower Sale** – 33 Alterra Blvd, Ancaster, on Saturday May 29 and Sunday May 30, 8:00 am to 3:00 pm. Shop early as last year was a sell-out.

For information for all these events call toll free: 1-866-377-4447 or 905-381-0475.

Kingston

Location: Loblaws Upstairs, Kingston Centre, Princess Street at Sir John A.

- Fourth Sunday each month, 3-4 pm. January 25, February 22, March 28, April 25, Winter season of informal thyroid information sessions. Bo Popovic, pharmacist and a representative from Kingston chapter will be present.

For information call: 613-530-3414.

Kitchener/Waterloo

Location: Kitchener Public Library, lower level. 85 Queen Street North, Kitchener. Wheelchair accessible.

- Wednesday, February 24, 2004, 7:00 pm. **Dr. Arshad Khan**, Psychiatrist, Kitchener. Topic: *The thyroid mind and emotions*.
- Wednesday, April 28, 2004, 7:00 pm. **Dr. Terri Paul**, Endocrinologist, Assistant professor, Endocrinology & Metabolism, St. Joseph's Health Centre, London. Topic: *Obesity: what you and your thyroid can do*. Annual meeting.

For information call: 519-884-6423.

London

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

- Tuesday, March 23, 2004. 7:30 pm. **Dr. John Wojcik**, Endocrinologist. Topic: *Thyroid cancer*.
- Tuesday, May 18, 2004, 7:30 pm. **Sheila Grose**, Dietitian, St. Joseph's Health Centre. Topic: *Food for thought!* New nutrition labelling guidelines, cholesterol and fat information in relation to weight control, healthy food choices and concerns regarding pre-diabetic diet.

For information call: 519-649-1145 or visit our website: www.thyroidlondon.ca.

- **Chapter Major Fundraiser, 4th Annual Dinner/Fashion Show** – Thursday, April 22, 2004. Hellenic Community Centre, 133 Southdale Road West, London, ON. Door prizes, draws, silent auction. Tickets now on sale for an evening full of fun. Buy tickets early to avoid disappointment.

Information and tickets call: 519-649-1145.

Toronto

The chapter is planning its spring event. For details and more information call the Helpline: 416-398-6184.

Thry'vors

Annual General Meeting

The Canadian Thyroid Cancer Support Group (Thry'vors) Inc. will hold its AGM at Wellspring, Oakville, Ontario on **Saturday, May 1, 2004**. For more information contact Thry'vors at PO Box 23007, 550 Eglinton Avenue, Toronto, M5N 3A8.

Helpful hint from Thry'vors:

Are you taking Cytomel (T3) because of an upcoming radioactive iodine (RAI) scan? Cytomel is faster acting than levothyroxine (Eltroxin, Synthroid, etc). If you find you get a big "buzz" from it or have trouble sleeping, ask your doctor if you can divide your dose into smaller quantities and take it several times a day instead of once or twice.

Has your address or telephone number changed?

We need to know!!

To ensure you receive your *thyrobulletin* and correspondence promptly, please send changes to:

Thyroid Foundation of Canada

PO Box 1919 Stn Main
Kingston ON K7L 5J7

Tel: 613-544-8364

Fax: 613-544-9731

E-mail: thyroid@on.aibn.com

Financial Statements

Thyroid Foundation of Canada/La Fondation canadienne de la Thyroïde

Year Ended March 31, 2003

Statement of Financial Position as at March 31, 2003

	<u>Operating Fund</u>	<u>Research Fund</u>	<u>Total 2003</u>	<u>Total 2002</u>
Assets				
Current Assets				
Cash and term deposits	\$53,139	\$328,219	\$381,358	\$ 236,495
Accrued interest		4,927	4,927	8,348
Accounts receivable	7,558		7,558	2,307
Prepaid expense	<u>9,882</u>	<u> </u>	<u>9,882</u>	<u>1,837</u>
	<u>70,579</u>	<u>333,146</u>	<u>403,725</u>	<u>248,987</u>
Investments				
Bonds (market value - \$102,039; \$225,082 in 2002)		<u>100,906</u>	<u>100,906</u>	<u>222,061</u>
	<u>\$70,579</u>	<u>\$434,052</u>	<u>\$504,631</u>	<u>\$ 471,048</u>
Liabilities and Fund Balances				
Current Liabilities				
Bank overdraft caused by outstanding cheques				\$ 7,091
Accounts payable	\$15,005		\$ 15,005	14,691
Deferred revenue	<u>42,311</u>		<u>42,311</u>	<u>34,578</u>
	<u>57,316</u>		<u>57,316</u>	<u>56,360</u>
Fund Balances				
Restricted fund – research		\$434,052	434,052	466,904
Unrestricted operating fund (deficiency)	<u>13,263</u>	<u> </u>	<u>13,263</u>	<u>(52,216)</u>
	<u>13,263</u>	<u>434,052</u>	<u>447,315</u>	<u>414,688</u>
	<u>\$70,579</u>	<u>\$434,052</u>	<u>\$504,631</u>	<u>\$ 471,048</u>

Research Fund Commitments (note 3)

Lease Commitment (note 4)

Approved by the Board:

Member, Ed Antosz, President

Member, Joan DeVille, Secretary

Statement of Cash Flow Year Ended March 31, 2003

	<u>2003</u>	<u>2002</u>
Cash Flow from Operating Activities		
Cash received from grants and donations	\$ 50,202	\$ 71,745
Cash received from class action settlement	50,820	
Cash received from membership fees	48,359	54,988
Cash received from Thyrobulletin funding	14,749	
Cash received from Nevada sales (net)	13,439	
Cash received from rental	2,052	
Cash received from Hedberg bequest	7,612	
Cash received from AGM	120	5,749
Cash received from books and education material	569	1,342
Interest and other	19,583	29,865
Cash paid for education, services and awards	<u>(176,706)</u>	<u>(233,119)</u>
Net cash from (used in) operating activities	30,799	(69,430)
Cash Flow from (used in) Financing Activities		
Sale (purchase) of investments	<u>121,155</u>	<u>(120,319)</u>
Net increase (decrease) in cash	151,954	(189,749)
Cash at beginning of year	<u>229,404</u>	<u>419,153</u>
Cash at End of Year	<u>\$ 381,358</u>	<u>\$ 229,404</u>
Cash is comprised as follows:		
Cash and term deposits	\$ 381,358	\$ 236,495
Bank overdraft		<u>(7,091)</u>
	<u>\$ 381,358</u>	<u>\$ 229,404</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, 2003 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 Canadian 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, 2003 and the results of its operations and cash flow for the year then ended in accordance with Canadian generally accepted accounting principles.

Secker, Ross & Perry

Secker, Ross & Perry
Chartered Accountants
Kingston, Ontario
October 15, 2003

continued on page 11

Financial Statements

Thyroid Foundation of Canada/La Fondation canadienne de la Thyroïde

Year Ended March 31, 2003

Statement of Operations And Changes in Fund Balances Year Ended March 31, 2003

	2003			2002
	Operating Fund	Research Fund	Total	Total
Revenue				
Grant – Health Canada				\$ 15,120
AGM revenue	\$ 120		\$ 120	5,749
Membership	47,834		47,834	54,488
Class action settlement	50,820		50,820	
Donations	45,738	\$ 4,464	50,202	54,596
Books and education material	569		569	1,342
Associate member organizations	525		525	500
Summer student grant				2,029
Administration fee – research	5,063		5,063	5,063
Interest and other	691	15,471	16,162	23,239
Thyrobuletin funding	14,749		14,749	
Nevada sales	38,420		38,420	
Rental income	2,052		2,052	
Hedberg bequest	<u>7,612</u>		<u>7,612</u>	
	<u>214,193</u>	<u>19,935</u>	<u>234,128</u>	<u>162,126</u>
Expenditure				
Education				
Health Canada projects				7,786
Chapter rebates – membership fees	18,087		18,087	22,047
Educational material	3,180		3,180	2,143
Publicity	817		817	817
Purchases for resale	29		29	389
Thyrobuletin (including mailing costs)	18,868		18,868	17,179
Meetings – annual	513		513	18,233
– other	<u>1,317</u>		<u>1,317</u>	<u>883</u>
Total Education	<u>42,811</u>		<u>42,811</u>	<u>69,477</u>
Services				
Nevada	24,981		24,981	
Office supplies and expenses	6,011		6,011	5,339
Postage and mailing	4,700		4,700	4,731
Professional fees – audit	1,700		1,700	1,700
Professional fees – contract accounting	3,850		3,850	3,250
Professional development – staff	594		594	180
Professional development – volunteers				250
Bank charges	1,138		1,138	531
Computer	1,122		1,122	2,651
G.S.T. expense	1,744		1,744	2,135
Insurance	3,390		3,390	2,405
Rent (includes services)	10,645		10,645	11,019
Salaries and benefits – office staff	40,861		40,861	39,936
Salaries and benefits – student				2,251
Telephone and fax	<u>5,167</u>		<u>5,167</u>	<u>4,225</u>
Total Services	<u>105,903</u>		<u>105,903</u>	<u>80,603</u>
Awards				
Doctoral award		10,224	10,224	9,765
Fellowship award – D.M. Abramsky		37,500	37,500	60,000
Student awards				9,000
Administration – operating		<u>5,063</u>	<u>5,063</u>	<u>5,063</u>
Total Awards		<u>52,787</u>	<u>52,787</u>	<u>83,828</u>
Total Expenditure	<u>148,714</u>	<u>52,787</u>	<u>201,501</u>	<u>233,908</u>
Excess of Revenue over Expenditure (Expenditure over Revenue)	65,479	(32,852)	32,627	(71,782)
Fund balances (deficiency) at beginning of year	<u>(52,216)</u>	<u>466,904</u>	<u>414,688</u>	<u>486,470</u>
Fund Balances at End of Year	<u>\$ 13,263</u>	<u>\$ 434,052</u>	<u>\$447,315</u>	<u>\$ 414,688</u>

Notes to Financial Statements Year Ended March 31, 2003

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 \$30,000 has been committed to Research Fellowships. In addition, an amount of up to \$8,000 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 five year lease expiring March 31, 2008 which calls for a monthly payment of \$1,145.



Highlights of 23rd AGM weekend

October 30 - November 1, 2003, Toronto, Ontario



Dr. Donald Pierson,
Southtown Consulting

The first day of the conference was devoted to a workshop examining the role and governance of the Thyroid Foundation of Canada (TFC). With the help of Dr. Donald Pierson of Southtown Consulting, we examined our strengths (there are many) and looked at his recommendations for improvements. We proceeded to prioritize the improvements he suggested, which was not an easy task as there are many areas where we need to start new and innovative structures and *modus operandi*.

Recommendations

The TFC would take on a different structure and operating method. One of Dr. Pierson's major recommendations was to decrease the size of the board to make operations, communications, etc. smoother. The suggestion was that the existing board reinvent itself by asking certain board members to voluntarily withdraw from the board. These

members, although no longer members of the board, would still be needed. Their contributions and work would be invaluable to support the board. Chapter presidents would contribute through chapter council. A transition board would be formed consisting of:

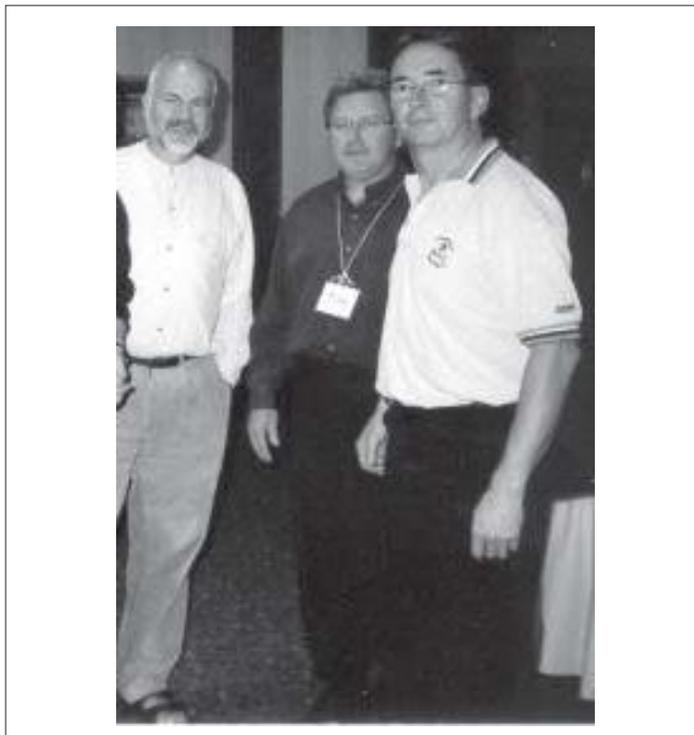
- president
- one vice-president
- secretary
- treasurer
- three chapter presidents
- past president

This would make communication easier, decision making more efficient and would allow the board to focus on policy rather than operations. The transition board would have the task of addressing the changes recommended in Dr. Pierson's report and presenting them for approval at the 2004 annual general meeting (AGM) in Toronto.

From Dr. Pierson's report the top five recommendations to be reviewed are as follows:

1. A standing ad hoc board development/governance committee should be established to address the findings of this review.
2. The board should hire an executive director or CEO and delegate operational responsibility within established guidelines or limitations; staff descriptions should be reviewed and revised if appropriate.
3. Suggest including articles related to ethical guidelines for corporate sponsorship, loyalty and confidentiality for board members and staff and conflict of interest. A code of conduct should be established and all board and staff members and volunteers should sign a pledge or oath of confidentiality and loyalty as part of their orientation process.
4. Suggest decreasing the board size to approximately 10 members to allow for inclusion of needed skills and distribution of workload. As initial steps, the board should review the need for inclusion of members-at-large and reduce or eliminate most chapter presidents as national board members and make use of the established governance representative body for chapters (i.e. chapter council established in 1989).
5. The board should develop a collectively shared multi-year plan, within the context of common values and guiding principles, that describes the vision of where it wants the Foundation to be in the future, a mission statement that indicates how the organization will get there, and strategic directions or goals that allow for an annual evaluation process to measure progress towards these goals.

The intent of recommendation No.1 will be met by the present executive who will appoint the ad hoc committee.



Ed Antosz, Rick Choma and David Morris
at the AGM 2003.

continued on page 13

This leaves us, in our top five priorities, with the recommendation to:

- Hire an executive director or CEO;
- Develop ethical guidelines for corporate sponsorship and a code of conduct;
- Develop a multi-year plan;
- Reduce the size of the present board.

The first priority could be implemented reasonably soon with the new position becoming financially sustainable through its own fundraising activity.

Some work has been done in the past to meet the requirement of developing ethical guidelines and the transition board will be able to build on this. Anyone who has done this type of work and has specific input is strongly urged to submit these ideas to the executive committee.

Development of the multi-year plan for the future of the organization will require the most work by the transition board.

Important progress was already made at the AGM workshop in the development of a vision statement letting the public know what we stand for and fulfilling the wishes of our founder, Diana Meltzer Abramsky.

With the election of the new president, the Foundation acquires a knowledgeable businessman to help us restructure and take us in the direction of our goal. Under his direction, we will be able to provide the leadership to continue to reach the one in twenty Canadians who have thyroid disease, to educate, and to raise the funds for the research that is needed to reach our goal of eliminating thyroid disease.

Friday, October 31 was taken up by board meetings for normal Foundation business and the 23rd AGM. During the AGM the new officers and members-at-large were elected (see masthead, page 4). The new board was elected with the same structure as provided for in By-Law No.1. The audited financial statements for the year ended March 31, 2003 were distributed and approved.

A vision statement was agreed upon:

“To provide leadership to eliminate thyroid disease”

Foundation's mailbox

We are preparing a book on Thyroid Cancer for patients and read with interest the vignette by Diane Patching in the summer edition of **thyrobuletin**. I would like to reprint the brief article in the section of our book in which patients recount their experience with thyroid cancer. May we have permission to do so?

Incidentally, we are listing your organization on the back of the book as a resource for patients.

*Leonard Wartofsky, MD, MACP
Chairman, Department of Medicine
Washington Hospital Center
Washington, DC, U.S.A.*

*Diane Patching and the Foundation
were happy to comply. Editor*

This is in reference to issue 24, No 1, Spring 2003. In the article *Complimentary and alternative medical therapies for thyroid disorders*, by Dr. Merrill Edmonds and Dr. John Wojcik, horseradish is discussed “*in very large amounts, however, it contains a substance which blocks the thyroid and can cause hypothyroidism*”.

I am hypothyroid and take 100 mcg plus one lactaid pill daily six times a week. I love horseradish.

1. What do you mean large amounts?
2. How much can one eat daily?

*Isabelle Leibovitch
Toronto, ON*

There is no simple response to the questions in your e-mail. A lot depends on whether the person has a underlying thyroid disease such as Hashimoto's thyroiditis since this would increase the susceptibility to anything that would tend to block the thyroid. Taking some horseradish every day might be just enough to push such a person into hypothyroidism. If the thyroid gland is normal though, it is very unlikely that a person would be able to eat enough

horseradish every day to block the thyroid. If the person is taking a full dose of thyroid hormone by mouth (75-150 micrograms daily) the horseradish should have little effect since the daily requirements will be met by the thyroid tablet. If a small dose of thyroid hormone is prescribed (less than 75 micrograms) the person's own thyroid would have to be making some thyroid hormone to keep the blood levels normal. This could, theoretically, be blocked thus necessitating an increase in the dose of the tablet to return the thyroid levels to normal.

*Merrill W. Edmonds,
MD, FRCPC FACP
St. Joseph's Health Care Centre
London ON*

I just wanted to let you know that I received the information package and found the literature really helpful. I signed my daughter up for the thyroid newsletter, picked up a couple of books on the suggested reading list, read everything and then gave it all to my daughter. We were discouraged because of all the conflicting information we had been getting. The pamphlets and books put a lot of issues into perspective. My daughter really appreciated the material too. She is feeling much better now that her medication finally kicked in – it's amazing what havoc one small gland can make when it's out of whack. Thank you for sending the thyroid information to me.

*Linda Lombard
Montreal, QC*



Thyroid disease and silent celiac disease

I would like to tell you my personal medical story because there may be other members of the Thyroid Foundation with similar conditions who could benefit from my experiences. I was diagnosed as hypothyroid in 1996. This was a relief as I had been feeling very tired and depressed for some time. The prescribed l-thyroxine helped, but I still did not feel really well. After joining the Thyroid Foundation and attending some of the meetings in Ottawa, I realized from the questions and discussions that many of the hypothyroid people were still feeling tired even if their TSH readings were in the normal range. This was my case, too. The experts continue to say that if the TSH is normal, your problem is not the thyroid gland.

My problem turned out to be celiac disease. I was diagnosed last May, much to my surprise, as I don't have the usual symptoms of celiac disease (CD). Celiac disease is a genetically mediated autoimmune disease that affects the small intestine. The common symptoms are gastrointestinal problems (often diarrhea and bloating), iron and folate deficiency anemias, weight loss, extreme fatigue, depression etc. In adults, the symptoms can be quite varied. The lining of the small intestine is damaged by gluten (a protein fraction) in wheat, barley, and rye, and so cannot absorb nutrients properly. After diagnosis by a biopsy of the small bowel, the only treatment is a strict gluten-free (GF) diet for life. Much more information on celiac disease and the GF diet is available at <www.celiac.ca>. The Canadian Celiac Association, like the Thyroid Foundation, helps sufferers adapt to living with a chronic condition.

My diagnosis was made only because I am married to a celiac (diagnosed in 1981), and we have always taken a great interest in following the latest research into CD. The relatively new *tissue transglutaminase* blood test made my diagnosis possible. I would never have been sent to a gastroenterologist, as I had no gastrointestinal symptoms. No doctor would have recommended a small bowel biopsy for me without the positive blood test. I consider myself extremely fortunate to have been diagnosed before my health deteriorated any further. (My main

by
Willow Wight



Willow Wight
member Ottawa Area Chapter

symptom was extreme fatigue. I have osteoporosis and am hypothyroid. My regular blood tests were normal.) I convinced my GP to order the *tissue transglutaminase* blood test – just in case. This test is quite new and not well known among family practitioners. But I spelled it out, and went to the lab to have blood drawn; they had not heard of it, but it was listed in their book. The test is not covered by OHIP, and cost me \$43. I am so glad it was available; a cheap and simple blood test has saved me years of misery. I had a small bowel biopsy about three months later, and the diagnosis was celiac disease. Since then, I have been on the gluten-free diet, have gained 15 pounds, and am feeling much more like a normal human being.

I do not have the classic form of CD, but “silent celiac disease” – the common gastrointestinal symptoms are absent. With silent CD, another autoimmune disorder such as thyroid disease, type I diabetes, anemia, chronic fatigue, osteoporosis, etc. is usually present. There are several informative articles available through the internet: in particular the excellent study done at the University of Maryland, <www.um.edu/news/releases/ceeliac_study.html>, published in February, 2003. This large study by Dr. Fasano and colleagues screened more than 13,000 people in the United States. One in 133 people who were NOT considered

at risk for CD actually had celiac disease. The prevalence of CD in first-degree relatives of celiacs was 1:22; in second-degree relatives, 1:39; and in symptomatic patients (with either gastrointestinal symptoms or a disorder associated with CD) 1:56.

Another very important article is “Celiac Disease – How to Handle a Clinical Chameleon”, an editorial by Dr. Fasano in the *New England Journal of Medicine*, 348; 25, p. 2568–2570; June 19, 2003. Written for physicians, this article presents new information on the atypical aspects of CD and its diagnosis. On the internet, this is available at <www.celiaccenter.org/news.asp> or <www.nejm.org>. It might be helpful to take a copy of these articles to your family doctor, as many GPs are not familiar with the latest information on CD.

Screening is recommended for people with a number of conditions (type I diabetes, thyroid and other autoimmune diseases, osteoporosis, etc.), who are at higher risk for CD than the general population. The newest blood test to screen for CD is the *tissue transglutaminase* test. It detects antibodies that are in the blood of celiacs who are consuming gluten. The availability of the blood test varies across the country. In Ontario, Gamma-Dynacare has it on their listing of available tests; it is not covered by OHIP and costs \$43.

A positive blood test must be followed up by a visit to a gastroenterologist for a small bowel biopsy **BEFORE** the gluten-free diet is started. If gluten is removed from the diet, the intestine will begin to heal and the biopsy will be inconclusive.

Because my husband had CD, it had always seemed very unlikely that I would have it too. But today we know that CD is not a rare disease! One gastroenterologist said recently that most of her patients now are diagnosed with CD after they have already developed another autoimmune disease. It seems that if you have one autoimmune disease you are at higher risk of developing another autoimmune disease. I suggest that others who have autoimmune thyroid disease and are still not feeling well even with a normal TSH should ask their doctors to consider celiac disease. It is not a rare disease.

Effects of combining T3 & T4 for the treatment of hypothyroidism

Combination hormone therapy does not benefit hypothyroid patients, says new study

Two articles in the current issue of the *Journal of Clinical Endocrinology and Metabolism (JCEM)* assess the effects of combining T3 and thyroxine (T4) supplementation for the treatment of hypothyroidism. The press release from The Endocrine Society describing these papers is reproduced below, dated October 3, 2003. The press release was reprinted from the website of Dr. Daniel Drucker, FRCPC, University of Toronto and Toronto General Hospital. Dr. Drucker maintains a comprehensive website devoted to all aspects of thyroid disease – www.mythyroid.com.

Combining two hormone therapies to treat the psychological affects of hypothyroidism may not be more effective than using a single therapy, according to new research articles published this month in the *Journal of Clinical Endocrinology & Metabolism*. Two new studies and an editorial question whether a combination of thyroxine (T4) and T3 is superior to T4 alone for the treatment of patients with hypothyroidism.

The new findings will be of great importance to the five to 10 percent of Americans who suffer from hypothyroidism, which occurs when the thyroid gland does not produce enough thyroid hormone. Symptoms of hypothyroidism can include fatigue, weight gain, thinned hair, decreased cardiac function, menstrual irregularities, sluggishness, dry skin and constipation.

One study, which was led by researchers from McMaster University in Hamilton, Ontario, specifically examined whether a combination of T4 and T3 therapy improved mood and sense of well being in hypothyroid patients who also suffered from depressive symptoms. In the prospective, double-blinded, randomized controlled trial, forty patients were randomized to receive either T4 therapy alone or a combination of T3 and T4 therapy. The results showed that when compared with T4 alone, the combination therapy did not improve either mood or personal sense of well being in the patients. The 15-week study was longer than any other previously published studies on this subject.

“Data does not support the routine use of T3 in addition to T4 to maintain euthyroidism in hypothyroid patients who are on stable doses of levothyroxine hormone, but who complain of depressive symptoms. Until a future large, multicentre, blinded, randomized, controlled trial proves otherwise, there is insufficient evidence to support changing the current approach of routinely using T4 alone to maintain euthyroidism in hypothyroid individuals,” explained Dr. Anna Sawka, the first author of the study.

A second study published this month in *JCEM* also compared a combination T4 and T3 therapy with T4. In the second study, which was a double-blind, random order, crossover trial, researchers from Sir Charles Gairdner Hospital in Perth, Australia compared the impact of the two treatments on quality of life, cognitive function and subjective satisfaction in 110 hypothyroid patients. In this study, approximately one-half of the subjects received T4 therapy for 10 weeks and then T4 and T3 therapy for 10 weeks. The other half of the subjects received the combination therapy first.

Once again, the researchers found no significant benefits for combination therapy compared to T4 alone. However, they did find that anxiety and nausea were significantly worse for patients on the combined therapy.

“At the conclusion of our trial, we found no benefit of combining T4 and T3 therapy on quality of life, hypothyroid symptoms, cognitive function, subjective satisfaction with therapy or treatment preference,” notes Dr. John P. Walsh, the senior author of the study. “Furthermore, we could not identify a specific subgroup of patients who benefitted from the combined therapy. Based on these findings, we believe that T4 alone should remain the standard treatment for hypothyroidism.”

In addition to the two new studies, the October issue of *JCEM* also includes an editorial by Drs. Michael Kaplan, David Sarne and Arthur Schneider, which discusses the use of T4 and T3 therapy to treat hypothyroid patients. In the editorial, the authors discuss the two new stud-

ies as well as previous research that examined T4 and T3 therapy. The authors write that based on past and current research, “evidence is fading that adding T3 to T4 is beneficial in the long-term treatment of hypothyroid patients with autoimmune thyroiditis.”

JCEM is one of four journals published by The Endocrine Society. Founded in 1916, The Endocrine Society is the world’s oldest, largest and most active organization devoted to research on hormones, and the clinical practice of endocrinology. Endocrinologists are specially trained doctors who diagnose, treat and conduct basic and clinical research on complex hormonal disorders such as diabetes, thyroid disease, osteoporosis, obesity, hypertension, cholesterol and reproductive disorders. Today, The Endocrine Society’s membership consists of over 11,000 scientists, physicians, educators, nurses and students, in more than 80 countries. Together these members represent all basic, applied, and clinical interests in endocrinology. The Endocrine Society is based in Chevy Chase, Maryland. To learn more about the Society, and the field of endocrinology, visit the Society’s website at www.endo-society.org.

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

Contributions to:
Rick Choma, Editor
Fax: (613) 542-4719
E-mail: rchoma@sympatico.ca

My thyroid cancer journey

by
Kim Graham

During a physical exam in the fall of 2001, my family doctor found a lump in the left side of my neck. That would be the beginning of my thyroid cancer “journey”. I often wonder how long it would have taken for me to notice the lump, had I not seen my doctor that day.

I was sent to see a highly recommended surgeon in Cambridge. Shortly after the initial visit, the surgeon performed a fine needle biopsy of the lump. When I met with him again, he confirmed that I had papillary carcinoma and that he wanted to surgically remove the left lobe only.

I was extremely naive and never even considered a second opinion. My mentality was that he was the expert and that a partial thyroidectomy was the best possible option (and the norm)! My first surgery was performed on December 14, 2001 at Cambridge Memorial Hospital. I think that it went very well, considering I was eating muffins the following morning! After the pathology was completed on the goitre, I soon found out that the right lobe would have to be removed as well. My second surgery was two months after the first, on February 13, 2002. This time around, my recovery was even better than before. The surgeon also told me that my right lobe contained a few smaller goitres. I was now thyroid-less.

In March, I found myself in London to see Dr. Tom McDonald for a follow-up appointment. After my discussion with him, I was sent for a routine ultrasound of my neck. Then, I was off to my home in Kitchener.

Dr. MacDonald called me at home a couple of evenings later. I knew it had to be bad news. First, he was calling me directly and second, it was in the evening. Dr. MacDonald told me that I was going to need another surgery. Apparently my right lobe was still there! I never even thought to ask him what it was they DID remove, if not my right lobe?

Surgery #3 was a whole new ball game. I went to the London Hospital and had Dr. John Yoo as my surgeon. Dr. Yoo explained that they may have removed either scar or fatty tissue during the second surgery. I was also told that I would be monitored very closely after this surgery, to make sure that my calcium lev-



Kim Graham with her son Nicholas

els didn't plummet. Following the surgery, my recovery went very well, and my calcium levels didn't even move.

My surgeries now officially over, it was time for radioactive iodine treatment through Dr. Al Driedger of London Health Sciences. Due to my history of depression, it was decided that I would be using Thyrogen to become hypothyroid. In November, two weeks after starting the low-iodine diet, I had my first radioactive iodine treatment.

I did not stay at the hospital for my seclusion. Instead, my mom and I “swapped” homes, and she looked after my 2 ½ year-old son. During this time, I read a lot and watched movies, but it was a very lonely experience. After five days, I was ready to go back home.

My son has always been good about separating from me, so he has been extremely accommodating with mommy's absences. When he initially saw my scar, and asked what it was, I told him mommy had an “ouchie”. After that, he wanted to kiss it better. Aren't kids the best?

After my treatment, it was discovered that the lab ordered the wrong blood test afterwards. Instead of a thyroglobulin test, they performed an antithyroglobulin

test. Because of this mistake, it was not known what effect the radioactive iodine had on my remaining thyroid tissue. Test results are not very often mixed up, in fact, I am only the second case that Dr. Driedger's office has seen this happen to.

I received a test dose of radioactive iodine this past September, and my thyroglobulin was below one. Now, my radioactive iodine chapter is over. I am guessing that those of us who get thyroid cancer are never done living chapters of the journey. By far, the most valuable lesson this experience has taught me is that no one is ever alone in their experience. In addition to the support and love of my family, I have found invaluable support from the “Thry'vors” listserve. Through reading the stories of others, I realize that I have been very lucky.

If anyone wants to contact me, my e-mail address is: kakes1969@rogers.com.

Meaningful words

Sometimes in our busy lives it is all too easy to forget the important words which can mean so much to those around us.

The six most important words:

I admit I made a mistake

The five most important words:

You did a great job

The four most important words:

What is your opinion

The three most important words:

If you please

The two most important words:

Thank you

The one most important word:

We

The least important word:

I



Call for nominations 2004-2005

Nominations are invited for the election of the officers and members-at-large on the Foundation's 2004-2005 national board of directors.

The nominating committee shall propose a nominee for the position of each officer and member-at-large to be elected (By-Law No. 1, clause 53). The slate of the nominating committee will be circulated to the members of the Foundation in the next issue of *thyrobulletin*. Additional nominations may be made from the floor at the time of the election which shall occur at the annual meeting of the members (AGM) on Saturday June 5, 2004.

The Board of Directors is comprised of:

- 1) officers who shall be elected annually by the members at the annual meeting;
- 2) the president of each chapter or a representative appointed by the chapter president, who shall be elected or appointed annually at the chapter level;
- 3) six (6) members-at-large who shall be elected by the members annually at the annual meeting;
- 4) the past president.

Officers of the organization are elected **annually** and shall hold the same office for no more than **three (3)** consecutive years (By-Law No.1, clauses 29 & 38).

Chapter presidents and members-at-large are elected annually for a term of **one year** and shall hold office until their successors are elected or appointed (By-Law No.1, clauses 18 & 20).

The current board has been challenged to review its current structure, consequently the slate presented by the nominating committee may constitute more positions than will be available.

Officers of the Foundation (executive committee members)

- President
- V-P Publicity & Fundraising
- V-P Chapter Organization & Development
- V-P Education & Research
- V-P Operations
- Secretary
- Treasurer

National members-at-large (6)

three of whom shall be:

- Editor, *thyrobulletin*
- Liaison, Medical Research
- Archivist

2003-2004 Nominating Committee:

- Ed Antosz**, Chair, Windsor, ON
Barbara Cobbe, London, ON
Gary Winkleman, Richmond, BC
Name, TBA
Name, TBA

Please contact the Chair at the address below if you wish to nominate someone, or if you are interested in serving as an officer of the Foundation, as a member-at-large or in assisting on a national committee. Nomination forms are available from your chapter, nominating committee members or the national office.

Please forward completed forms to:

Ed Antosz
Nominating Committee Chair
1508 - 75 Riverside Drive
Windsor, ON N9A 7C4
Tel: 519-253-2885
Fax: 519-971-3694
E-mail: antosz@uwindsor.ca

Deadline: Monday March 15, 2004

Mark your 2004 calendars . . .

Saturday morning

June 5

Patient Thyroid
Update Forum



Saturday

June 5

2:00 pm

Annual General Meeting

Friday

November 12

2nd Annual Gala



Saturday

November 13

Professional

Day for Family Medicine

Details to follow!

Thyroid Foundation of Canada
La Fondation canadienne de la
Thyroïde

24th AGM
Annual General Meeting

Saturday

June 5, 2004

2:00 pm

Toronto, Ontario

Members of the Foundation
and the general public are
welcome to attend.

Joan DeVille,
National Secretary

Grief and depression

Grief is the feeling generated by a loss and is a process. The typical pattern can give us a picture of “normal” depression. In the community there is still a tendency to think of grief solely as a response to death, especially of someone we love, but in recent decades the understanding of human psychological processes has grown enormously and we now know that loss of any kind can provoke a grief reaction. Loss of health such as in Chronic Fatigue Syndrome, loss of a body part due to surgery or accident, loss of a job due to redundancy or retirement are all obvious examples of loss. Less obvious losses can include infertility (loss of the expectations of rearing your own children) and divorce (loss of the expectations of a life-time shared in marriage which may also be associated with financial loss and loss of expected lifestyle).

Psychology experts have put together the following pattern of grief reactions. It must be emphasized however that your own experience is unique and there are great variations, both in the pattern of grief and in the time it takes to work through.

- **Disbelief** – There is an initial response of shock, numbness and disbelief which is usually short-lived and followed by;

- **Preoccupation** – Longing and yearning for what you have lost fills your mind.

There may also be;

- **Denial** – Acting as though the loss had not occurred (keeping a bedroom ready for a dead child) or if retrenched (getting dressed and going “to work” every morning) or in Chronic Fatigue Syndrome (pushing yourself past the point of what you know is appropriate);

- **Anger and guilt** – Intense emotions which may be expressed in statements such as “Why has this happened to me?”; “It’s not fair!”, or “If I had only done such and such this would not have happened”. This usually settles to be slowly replaced by acceptance of the loss;

- **Acceptance of the loss** – with continued grieving and, finally,

- **Depression.**

by
Dr. Nicole Phillips

The depression associated with grief usually lessens although at times it may seem that it will never lift. Anniversaries of the death or of a distressing event, birthdays and other reminders may reactivate your feelings but gradually the strands of life are picked up again and you return to normal functioning (this of course not being applicable to Chronic Fatigue Syndrome patients). This usually occurs around a period of 13 months and most people feel they are coping much better in the second year. The important message here is that grief and the depression accompanying it should heal over time. If you remain depressed and unable to get on with life it could indicate unresolved issues related to the loss and possibly the onset of a depressive illness.

Depression

The number and severity of the losses that accompany the diagnosis of Chronic Fatigue Syndrome, in my experience, cause a very high incidence of co-existing depression along with the Chronic Fatigue Syndrome symptoms. Because many of the symptoms of depression and Chronic Fatigue Syndrome overlap it takes someone knowledgeable about both these conditions to tease out what is what and make appropriate diagnoses. The symptoms that overlap include fatigue, sleep disturbance, difficulty concentrating and remembering things, loss of libido, bodily aches and pains. However, in my experience the essential differences are:

1. In Chronic Fatigue Syndrome without depression the patient’s mood tends to be more that of frustration and anger whereas in depression the patient’s mood drops markedly and has a quality of hopelessness and negativity much more severe than in the non-depressed person. There is an overall sense of inability to cope, tearfulness, heightened sensitivity to perceived criticism and difficulties in interpersonal relationship.

2. In depression, anxiety is a major symptom and so if anxiety levels are raised substantially this is usually a good indicator of depression.

3. Thoughts of death or suicide are also a good indicator of depression. Sometimes these are more passive such as thoughts of “I’d rather not be here” or “It wouldn’t matter if I was run over by a bus” rather than active thoughts and plans.

4. Importantly, in depression there is always a substantial loss of pleasure or interest in things that previously people enjoyed. The important thing here is that in Chronic Fatigue Syndrome many or most of these previously enjoyed activities can no longer be undertaken due to illness. The giveaway though is that if someone is experiencing depression they don’t even have the desire to be doing these things any more such as seeing people, going to a movie or doing the things they enjoyed doing previously, as opposed to people with Chronic Fatigue Syndrome without depression who say they would still love to do these things if only they were feeling better.

From my experience, if there is any uncertainty about whether depression exists or not in someone with Chronic Fatigue Syndrome, a trial of antidepressants is useful. Much of the emotional suffering in the illness can be relieved by the use of antidepressants if there is a concurrent depression present. If they cannot be tolerated or in fact make no difference, then nothing has been lost and they can be ceased.

Making a diagnosis of depression should not in anyway take away from the concurrent diagnosis of Chronic Fatigue Syndrome. Unfortunately there are still many false and hurtful beliefs about depression such as the sufferer can pull himself or herself together which only adds to the burden of guilt that people are already experiencing or that a diagnosis of depression means that you are weak-minded or mentally incompetent or that there is no visible problem therefore there is no problem at all. Often the depressed

continued on page 19

person feels that someone has “caused” the depression and often a parent, sibling or important role model gets the blame. Sometimes the depressed person feels that they have in fact committed an unforgivable sin and is being punished. There are many other myths and fallacies about depression which is a treatable illness like any other medical illness.

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Time To Renew?

Just a reminder that your membership in the Foundation, which includes your quarterly edition of *thyrobulletin* may be running out. Please check the expiry date on the address label and renew today to ensure that you’ll continue to receive our informative newsletter.

You can renew your membership early, for one or two years, and donations are always welcome! You again become eligible for our monthly book draw.

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

www.thyroid.ca/english/membership.html

*Thank-you for supporting the
Thyroid Foundation of Canada.*

Membership/Donation Form

Awareness  Support  Research

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

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**I will support the
Thyroid Foundation
of Canada!**

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

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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

NOVA SCOTIA/NOUVELLE ÉCOSSE

Halifax (902) 477-6606

PRINCE EDWARD ISLAND/ÎLE-DU-PRINCE ÉDOUARD

Charlottetown (902) 566-1259

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

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Burlington/Hamilton (905) 381-0475
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London (519) 649-5478
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Petawawa/Pembroke (613) 732-1416
Sudbury (705) 983-2982
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Toronto (416) 398-6184

* Area Contact/Contact régional

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