



# Thry'vors News

CANADIAN THYROID CANCER SUPPORT GROUP (THRY'VORS) INC.

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## What Should I Eat?

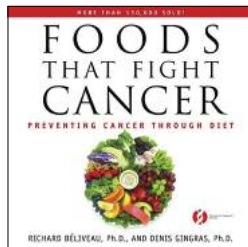
by Grace Wright

In September 2008, Richard Béliveau author of *Foods That Fight Cancer*<sup>1</sup> was the guest speaker at an event in Toronto. He provided a hand out of information that all cancer patients may be interested in considering.

Dr. Béliveau's lecture was based on his book. It was written with colleague and fellow scientist Denis Gingras, and has been translated into 18 languages from the original French. The authors worry that "we have lost respect for the food we eat – and for our bodies. We take more care in choosing the gas for our cars than the food for our bodies."<sup>1</sup>

Dr. Béliveau's lecture handout included the following:

"We currently believe that dietary choices are responsible for more than one third of cancers, showing the importance of a healthy diet in order to reduce both cancer incidence and its progression. A number of fundamental clinical and epidemiological studies have shown that increased fruit and vegetable intake represents a key factor in reducing cancer risk.



As a matter of fact, these foods contain a large quantity of phytochemical components that play a crucial role in this chemopreventive effect.

Aside from fruits and vegetables, recent research work has shown that other foods less common in our Western diet, such as green tea, garlic, soy, and turmeric spice, also contain large quantities of anticancerous components. These types of foods are called nutrimeids.

Incorporating these nutrimeids into the daily diet increases the absorption of anticancerous phytochemical components by up to 1 to 2 g per day. A daily intake of these different foods in the diet is a simple and effective way to counter the progression and development of cancer."

This is the 24<sup>th</sup> in a series of seasonal newsletters, from the Canadian Thyroid Cancer Support Group (*Thry'vors*) Inc. Your comments and suggestions are most welcome.

Please direct your comments to the Newsletter Committee at [thryvors@sympatico.ca](mailto:thryvors@sympatico.ca)

### Editor's Note:

It's hard to believe summer is over. *Thry'vors* has had a busy few months, including a successful patient forum in Toronto as well as partnered events in Edmonton and Surrey. Toronto also played host to the World Congress on Thyroid Cancer 2009. Many of our members were in attendance – look for notes from the conference in our upcoming issue. Well done *Thry'vors*!

Sarah Lyons, *Editor*

[www.thryvors.org](http://www.thryvors.org)

Canadian Thyroid Cancer Support Group (*Thry'vors*) Inc.

PO Box 23007  
550 Eglinton Ave. West  
Toronto, ON M5N 3A8

Phone: 416-487-8267  
Fax: 416-487-0601  
Email: [thryvors@sympatico.ca](mailto:thryvors@sympatico.ca)

*Offering information and support*



**Guide for Preventing Cancer Through Diet**

| List of NutrimeDs                             | Suggested Quantity/Day     |
|---|----------------------------|
| Brussel sprouts, cabbage, cauliflower, turnip | ½ cup                      |
| Broccoli                                      | ½ cup                      |
| Tomato paste                                  | 1 tbsp                     |
| Dark Chocolate (70%)                          | 30 g                       |
| Blueberries, raspberries, blackberries        | ½ cup                      |
| Tumeric                                       | 1 tsp                      |
| Green tea                                     | 3 times 250ml              |
| Raisin  | ½ cup (or 200 ml of juice) |
| Soy   | ½ cup                      |
| Ground linseed                                | 1 tbsp                     |
| Onion, shallots, leek                         | ½ cup                      |
| Black pepper                                  | ¼ tsp                      |
| Garlic  | 1 tsp                      |
| Dried cranberries                             | ½ cup                      |
| Spinach, watercress                           | ½ cup                      |
| Red wine                                      | 1 glass                    |
| Citrus fruit juice                            | ½ cup                      |

~~~~~  
 1 Foods That Fight Cancer, Preventing Cancer through Diet, by Richard Béliveau and Denis Gingras, McClelland & Stewart ISBN: 978-0-7710-1135-1 (0-7710-1135-0) 2006

2 “Fighting cancer, a forkful at a time” Susan Schwartz, The Gazette, Wednesday, October 17, 2007

~~~~~  
*Richard Béliveau is a leading authority in the field of cancer research. He holds the Chair in the Prevention and Treatment of Cancer at the University of Quebec at Montreal, where he is a professor of biochemistry. He is the director of the Molecular Medicine Laboratory of UQAM—Sainte-Justine Hospital (Centre de cancérologie Charles-Bruneau) and is also a professor of surgery at the Faculty of Medicine at the University of Montreal.*

**An Introduction to Thyrogen®**

Thyroid cancer patients are often prescribed a drug called Thyrogen® (recombinant TSH) to prepare for radioactive iodine (RAI) scanning, treatment and/or for stimulated Thyroglobulin (Tg) testing. Thyrogen® stimulation is also considered by many clinicians to be part of a life-long protocol of follow-up for all patients with differentiated forms of thyroid cancer.



**What is Thyrogen®?**

Thyrogen® replaces the need to have patients withdraw from their thyroid hormone replacement – the latter being a process that renders patients hypothyroid and normally takes at least six weeks. Thyrogen® is fast-acting, causing the TSH to rise very rapidly over a few days. Since it is given by injection, it requires visits to a doctor or nurse for the shots. Patients are given two doses – typically the first on a Monday and the second on Tuesday. The patient receives a dose of RAI on Wednesday (if necessary). The optional scan as well as the blood work for Tg testing are performed on Friday. Patients, who are not having a Whole Body Scan (WBS) or treatment with RAI, just have the Tg blood test. This blood test is known as a “stimulated Tg”. It is important for patients to have a good understanding of this routine, so that they can be sure the protocol is followed, especially that the blood lab technician or staff person is reminded that when she withdraws blood to be sure she enters the lab information as a Tg test and Tg-Ab test (not a TSH test, although that may be done additionally).

As well, doctors have the option of using Thyrogen® in order to raise the TSH for an ablative (treatment) dose of RAI. In that case, the scheduling is slightly amended. The ingestion of the RAI is the same as described above but the WBS may be one week after the ingestion of RAI, rather than on the Friday of the first week.

Not only does the TSH go up rapidly with the help of Thyrogen®, it also declines quickly too. Similarly, the RAI leaves the body (via the kidneys) more rapidly than it does with hypothyroid preparation. Therefore some doctors

recommend that patients have a slightly higher dose of RAI with a Thyrogen® preparation to ensure effectiveness (ie. minimum of 4mci for a test dose<sup>1</sup>, and 100mci<sup>2</sup> for a treatment dose). It has also been argued that the more rapid clearance of RAI from the body when using Thyrogen®, means there is less toxicity to the body from the treatment.<sup>3</sup>

Most patients have few side effects from Thyrogen® and are delighted to avoid becoming hypothyroid (“going hypo”).

A Thyrogen® kit contains two small bottles of the Thyrogen® fluid that must be mixed with sterile water prior to intramuscular injection by your doctor. Sterile water is NOT included in the kit and must be provided by your pharmacist. **Before leaving the pharmacy with your Thyrogen®, ask to make sure that sterile water has been added to your order.** Some pharmacies charge a small fee for the water.

### Cost Coverage

One of the challenges a patient faces is trying to understand which drugs are covered by the government, special drug programs, private insurance, or alternatively have to be paid for by the patient.

In Canada, provinces determine whether or not a drug is covered under government programs, and define the terms of coverage. Many provinces have approved full cost-coverage for Thyrogen® and patients need not concern themselves with cost issues.

If your province of residence does not cover the cost of Thyrogen®, you may have cost (partially or completely) covered by your private health insurance program. You will need to provide your insurer with the Drug Insurance Number (DIN) for Thyrogen® and ask if your policy covers the cost. You may need to complete a special form, as required by your insurer to determine coverage.

### Big Announcement!

As of August 2009 Thyrogen® has been given an “indication” by Health Canada for use as a therapy for the ablation of thyroid tumour remnants in patients who have thyroid cancer tumours. That is, Thyrogen® has now been given full approval for use in patients, as an alternative to being withdrawn from thyroid hormone replacement drugs for RAI treatment. This approval is in addition to its previous formal approval for scanning or Tg testing.

The Drug Insurance Number (DIN) for Thyrogen® is 02246016.

In regards to Thyrogen®, it has been estimated by the manufacturer’s research that approximately 1/3 of Canadian patients have provincial government coverage, 1/3 have private health insurance coverage, and 1/3 pay out-of-pocket.

### Help to Navigate Through Drug Cost Coverage Options

The manufacturers of Thyrogen®, Genzyme Canada Inc., have set up a Helpline to assist patients in determining if the drug is covered by their insurance plan, and how to go about being reimbursed. Ontario also provides assistance in determining the cost-coverage options through the Cancer Drug Assistance Program of Cancer Care Ontario.

### Thyrogen® Reimbursement Helpline

The manufacturer of Thyrogen®, Genzyme Canada Inc., has set up a helpline to assist with determining if the drug is covered by your private insurance plan, and how to go about being reimbursed.

The number to call is: **1-866-401-8323**

The Thyrogen® Reimbursement Helpline is open from 8:00 am until 8:00 pm EST. Monday through Friday.

### For Ontario residents only:

Cancer Drug Assistance Program, Cancer Care Ontario

[www.cancercare.on.ca/english/home/toolbox/drugs/ndfp/cdap/](http://www.cancercare.on.ca/english/home/toolbox/drugs/ndfp/cdap/)

Cancer Care Ontario’s Cancer Drug Assistance Program (CDAP) helps patients find opportunities for reimbursement for costly cancer treatments. This bilingual pilot program does not provide direct reimbursement to patients, but rather provides information and advice to patients and their families about drug coverage options.

CDAP’s toll-free support lines are answered by specially trained nurses. CDAP operates on regular business days, Monday to Friday from 8am to 8pm EST. Contact CDAP by phone or fax.

Phone: **1-877-681-6551** – verbal consent required

Fax: **1-877-681-6552** – written consent required

A third-party translation service is available for special cases, in over 120 languages.

**Pricing: Do Your Research Before Purchasing Thyrogen®**

The following information may save you some money if you have to buy Thyrogen®, or pay for a percentage of it under your insurance plan. The consumer cost of Thyrogen® can vary by over \$172.00 per kit, depending upon where you buy it.

As the manufacturer, Genzyme Canada Inc. provides Thyrogen® for \$1324.00 per kit. Some pharmacies do not purchase it directly from Genzyme but rather they buy it from wholesalers, who mark it up by approximately 5.5%, thereby making the cost to the pharmacy \$1396.82. Then the pharmacy can make a 10-20% mark up when they sell the drug to customers.

Ontario does not cover the cost of Thyrogen® under the provincial health plan (except for those who meet the criteria of the Ontario Drug Benefit Program). Here are some specific Ontario examples of the consumer price differences, surveyed September 2008 (costs include drug retail price and pharmacy dispensing fee):

|   |           |
|---|-----------|
| Mount Sinai Hospital Pharmacy – Toronto             | \$1456.40 |
| Shoppers Drug Mart – Guelph (Silvercreek Parkway)   | \$1505.99 |
| Shoppers Drug Mart – Downtown Toronto (Queens Quay) | \$1534.59 |
| Walmart Pharmacy – Etobicoke                        | \$1545.47 |
| DRUGstore Pharmacy – Guelph (Silvercreek Parkway)   | \$1560.00 |
| IDA Pharmacy – Scarborough                          | \$1628.32 |

**LID RECIPE BOX**

**Mexican Tomato Lime Soup**



- 4 cloves of garlic, minced
- 2 tsp ground cumin
- 1 tbsp oil
- 6 cups tomato juice
- 2 cups fresh tomatoes, chopped
- juice of one large (or 2 small) limes
- 3 tbsp chopped cilantro (optional)
- hot pepper sauce to taste (like Tobasco or ½ tsp chilli flakes)
- Optional topping: baked no-salt corn tortillas

In soup pot, sauté the spices in the oil – don't brown the garlic. Add tomato juice, fresh tomatoes, lime juice and cilantro (if using). Gently bring to a simmer and heat through completely. Add hot sauce to taste.

Baked tortilla chips: Brush oil on no-salt tortillas. Sprinkle with non-iodized salt or other spice like basil. Cut in strips or triangles. Place on baking sheet & bake 325 F for approximately 5 minutes until light brown and crisp. Serve on top of soup.

New Recipes are continuously added to the *Thyroid* LID Recipe Index - now including almost 400. To view LID recipes, go to: <http://health.groups.yahoo.com/group/Thyroid> or view a sampling of recipes at [www.thyroid.org](http://www.thyroid.org)

In these few examples, the price varies by as much as \$ 172.00

Lesson: If you need to purchase Thyrogen®, call pharmacies and ask what you will be charged BEFORE you decide where you will buy it. Thyrogen® is becoming much more widely available than it was in the past, and more pharmacies are either stocking it or have quick access to it.

More information on Thyrogen®, please consult *Thyroid* website:  
*Thyroid* Information Sheet: Thyrogen® – Updated September 2008, by Patricia Sharkey  
[www.thyroid.org/pdf/Thyroid\\_thyrogen.pdf](http://www.thyroid.org/pdf/Thyroid_thyrogen.pdf)

1. Genzyme Corp. package directions for Thyrogen® [www.thyroid.com/healthcare/about\\_thyrogen/p\\_hc\\_about-use.asp](http://www.thyroid.com/healthcare/about_thyrogen/p_hc_about-use.asp)
2. Dr. AA Driedger, Ask *Thyroid* Compilation, page 35 [www.thyroid.org](http://www.thyroid.org)
3. Pacini F, Ladenson PW, Schlumberger M, et al. Radioiodine ablation of thyroid remnants after preparation with recombinant human thyrotropin in differentiated thyroid carcinoma: results of an international, randomized, controlled study. 2006; J Clin Endocrinol Metab.91:926–932.

## Ask Thry'vors

by Mia Guilló

The members of *Thry'vors* Medical Advisory Panel are available to answer YOUR general questions about every aspect of thyroid cancer. A list of our Medical Advisory Panel members appears on our website at: [www.thryvors.org/AboutThryvors.html](http://www.thryvors.org/AboutThryvors.html)

### In This Issue:

We ask about weight loss following thyroidectomy surgeries. Dr. Shereen Ezzat and Dr. Alice Y.Y. Cheng — members of *Thry'vors* Medical Advisory Panel — assist us with their responses.

### Question:

Some people gain a fair amount of weight in the year after their thyroidectomy surgeries. Some report that normal diet and exercise to reduce weight is not always as effective as it was pre-surgery. A patient asks if the weight will naturally come off, or if extra hard measures will have to be taken to get the weight off due to TSH level variables.

### Reply by Dr. Shereen Ezzat:

It's true that thyroid hormone levels can fluctuate widely in patients undergoing total thyroidectomy. For most, correction with synthetic thyroid hormone restores levels to their normal state and corrects the associated symptoms of fatigue and weight gain. For unclear reasons, however, some patients continue to battle with perpetual weight gain despite thyroid hormone replacement. It is advisable to take preventative measures by maintaining a regular exercise and dietary routine to avoid post thyroidectomy weight problems.

### Reply by Dr. Alice Y.Y. Cheng

After a total thyroidectomy, every effort is made to achieve a normal thyroid hormone level as soon as possible. Therefore, there should be little impact on weight. However, there is a period of time immediately after surgery when some patients may reduce their activity levels and that may result in some weight gain. Once the TSH free T4 and free T3 levels have been normalized, the weight should stabilize and patients need to reduce their oral intake and increase their physical activity as needed to

lose weight. As is always the case with weight management, every individual is different and even within the same individual, different times in their lives will also affect the ability to lose or gain weight.

### Special thanks to:

Special thanks to Dr. Shereen Ezzat, FRCP(C), FACP Professor Of Medicine & Oncology Head, Endocrine Oncology – Mount Sinai & Princess Margaret Hospitals and Dr. Alice Y.Y. Cheng, FRCP(C), Endocrinology And Metabolism, Assistant Professor - University Of Toronto for their participation in this edition of Ask *Thry'vors*.

### A New Way to Donate



*Thry'vors* is now a member of Shoppers Drug Mart's Optimum Points program. That means, if you have a Shoppers Drug Mart Optimum Points card, you can donate your accumulated points (or any part of them) to *Thry'vors*. In turn, *Thry'vors* can make use of the points donated towards purchases at Shoppers Drug Mart stores.

To get an Optimum Points card, print an application from the Shoppers website or ask any cashier for a copy of the application. You will receive your card immediately. Present your card each time you make a purchase to accumulate points. At your convenience go online to donate your points to *Thry'vors*.

For information or to donate your points, visit:



[www.shoppersdrugmart.ca/english/optimum/donate\\_points/index2.html](http://www.shoppersdrugmart.ca/english/optimum/donate_points/index2.html)

## A Day In My Life...

by: Cherylyn (Edmonton)

My eyes continually roll around  
Within my foggy head  
I just don't want to make a move  
And yet can't stay in bed.

I know if I could sit here  
I would probably fall asleep  
And surely land upon the floor  
In one gigantic heap.

My eyes are like a faucet  
With their constant drip, drip, drip  
And I know that I could fix them  
If I could only get a grip.

I seem to ride a roller coaster  
Up and down through out the day  
And every once in a while  
Things seem to go my way.

Some days are good and some are bad  
And yet I can't decide  
Of which of these I am content  
And of which I want to hide.

So if you see me in a fog  
And don't know what to do  
Count to 10 and wake me up  
And we'll laugh until we're blue!

**Send us your poems.**

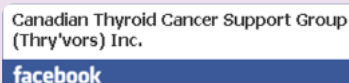
**Email: [thryvors@sympatico.ca](mailto:thryvors@sympatico.ca)**

### Resources in the File Section of *Thry'vors* Online Forum

*Thry'vors* Online Forum is not just a great place to chat with other members of our group on-line. It is also a place where we store lots of reference material for you to access in one place on the internet.

<http://health.groups.yahoo.com/group/Thryvors/files>

We're also on Facebook



## Quality of Life After Recovery from Thyroid Cancer

An article review by Charna Gord, BASc, MEd, RD

*Charna Gord is a Registered Dietitian working as an Education Coordinator in an Ontario public health unit. She underwent a total thyroidectomy for thyroid cancer in December 2007. This is the sixth in a series of thyroid cancer related journal articles and other resource reviews that Charna has undertaken for Thry'vors News.*

In this review, Charna summarizes the findings of the following journal article:

**Sawka AM, Goldstein DP, Brierley JD, Tsang RW, Rotstein L, et al. (2009) The Impact of Thyroid Cancer and Post-Surgical Radioactive Iodine Treatment on the Lives of Thyroid Cancer Survivors: A Qualitative Study. PLoS ONE 4(1): e4191. doi:10.1371/journal.pone.0004191**

Long term quality of life for thyroid cancer patients was studied in this article, with special emphasis on those recovering from radioactive iodine treatment (RAI). The research objective was to look at the experience of thyroid cancer from the point of view of a thyroid cancer patient. The researchers asked thyroid cancer survivors what they would want to tell future patients and healthcare providers about thyroid cancer care, based on their experiences; getting the initial diagnosis, the counselling and decision making related to radioactive iodine therapy (RAI), and any consequences of treatment.

Three focus group sessions moderated by a medical facilitator and qualitative researcher were held in Toronto in July, 2007. The participants were made up of 16 people, of which 12 were women. They had all undergone surgery for well-differentiated papillary or follicular thyroid cancer as well as having been offered RAI. Participants were anywhere from 28 to 75 years of age, had received their initial diagnosis between 2 and 8 years prior, and about three-quarters had a university education. They were all recruited from the University Health Network and Mount Sinai Hospital in Toronto through flyers posted in clinics.

The three themes identified in the focus group sessions and the details for each theme are as follows:

*Theme 1. The life-changing experience of a thyroid cancer diagnosis.*

- 1) The experience changed their lives and outlook on life.
- 2) Feelings of fear and uncertainty about the future followed the diagnosis.
- 3) Being told thyroid cancer was a “good cancer” was generally not reassuring and made patients feel that their diagnosis was being dismissed as unimportant.
- 4) Support from family, friends and health professionals was appreciated.

*Theme 2. The experience of receiving counselling and decision-making on adjuvant RAI treatment.*

- 1) Thyroid cancer specialty physicians were considered the primary information source for thyroid cancer treatment.
- 2) Patients received contradictory information about RAI from physicians and the internet.
- 3) Patients wanted plain language information about the risks, benefits and uncertainty of RAI.
- 4) Some patients wanted quantitative information on disease prognosis and treatment benefits while others didn't.
- 5) Patients felt internet information wasn't necessarily relevant to their case.
- 6) Some patients wanted involvement in RAI decision-making, while others didn't.

*Theme 3. The experience after RAI treatment.*

- 1) More than half of participants reported some short- or long-term emotional or physical negative effects from RAI.
- 2) These side-effects were not always recognized by physicians at follow-up.

The research participants came up with four recommendations for physician counselling of future patients about RAI treatment. Physicians should provide:

1. An explanation for the rationale for (or against) RAI at an individual case level.
2. Plain language information on the benefits, risks and uncertainties of RAI due to limited high quality evidence or controversy. In particular three areas of concern were highlighted: information on implications for women of reproductive years who might want to get pregnant, the risk of a second primary cancer and the risk of recurrence.
3. A multi-disciplinary team-based, individualized approach to treatment. Conflicting recommendations between practitioners should be avoided by adopting open communication.
4. A discussion about current clinical practice guidelines as they relate to the individual case of the patient.

The authors conclude by affirming that long-term and late side effects experienced by cancer patients are receiving increased recognition in the cancer care literature. Therefore a comprehensive care summary and follow-up plan that is clearly explained might reduce uncertainties and potential anxiety to the disease course and any treatment-related side effects. Looking at the impact on physical, mental and emotional health of thyroid cancer patients who receive this kind of information deserves future study.

**Tell us what you think**

Your comments and suggestions are welcome.



Graphic Design and layout provided by [www.litmusdesign.ca](http://www.litmusdesign.ca)  
(ursula@litmusdesign.ca)



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**THANK YOU**



Thy'vors would like to thank Sunrise Senior Living, Thorne Mill on Steeles, for providing meeting facilities for our monthly Executive meetings. For more information on Sunrise Senior Living, contact [www.sunriseseniorliving.com](http://www.sunriseseniorliving.com).

## Upcoming Events

### Wine Tasting and Silent Auction (Halifax)

**Who:** Interdisciplinary Thyroid Oncology Clinic, Halifax

**Date:** September 19th, 2009

**Time:** 7:00 to 9:00 pm

**Location:** Saint Mary's University, Halifax, Nova Scotia

The Interdisciplinary Thyroid Oncology Clinic (ITOC) in Halifax are holding their first fund raising event to help improve patient care and research using customized computer programs. Wines from the Mediterranean region will be sampled and discussed. Five food and

wine pairings will be served. There will be a silent auction. Cost: \$45 per person.

To make a silent auction donation, purchase individual or group tickets, or make a donation to the clinic, please contact the ITOC in Halifax at or Carol at (902) 425-8228.



### Thyroid Cancer Survivor's Conference

**Who:** ThyCa: Thyroid Cancer Survivors' Association, Inc.

**Date:** October 16 - 18th, 2009

**Location:** Sheraton Ferncroft Hotel, Boston, Massachusetts (United States)



- For everyone whose life has been touched by thyroid cancer - people being tested, those newly diagnosed, long-term survivors, people with advanced disease, caregivers, and friends.
- More than 80 sessions. The latest research, advances in treatment and follow-up, insurance and employment issues, and coping skills for well-being.
- Featuring leading physicians and other specialists - more than 50 speakers.
- Learn from experts. Share experiences with others coping with thyroid cancer.

### Registration information:

- Regular \$50; Annual members \$40; Lifetime members \$35; Added family members/guests \$30
- Early-bird discount: \$5 off if postmarked or sent online by September 16, 2009.
- Scholarships available.
- Walk-in attendees welcome. Sessions from 8 a.m. to 5:15 p.m. Friday and Saturday; 8 a.m. to 3:30 p.m. Sunday. There are 5-6 choices of topics and speakers in different rooms at each time period during the day.
- Hotel's special room rate for conference attendees: Single, double, triple, or quad room \$99 plus tax.
- Free parking. Near I-95/128 and I-93. Nearest airports are Boston's Logan Airport & Manchester, NH.

For additional information or to register, contact [www.thyca.org](http://www.thyca.org) or [conference@thyca.org](mailto:conference@thyca.org) or [thyca@thyca.org](mailto:thyca@thyca.org) or 1-877-588-7904.

**Like you, we have been touched by thyroid cancer. We are a non-profit organization and we are all volunteers. If you would like to donate or to become a volunteer please visit [www.Thryvors.org](http://www.Thryvors.org).**

**Donation cheques can be made payable to:** Canadian Thyroid Cancer Support Group (*Thry'vors*) Inc.

**Mail to:** Canadian Thyroid Cancer Support Group (*Thry'vors*) Inc.  
PO Box 23007, 550 Eglinton Ave. West  
Toronto, ON M5N 3A8

**Make a donation online today.**



**[www.canadahelps.org](http://www.canadahelps.org)**

**enter the word *Thry'vors***

[www.thryvors.org](http://www.thryvors.org)