



Thry'vors News

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Thyroid Cancer Canada
Cancer de la thyroïde Canada

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New Year, New Decade, New *Thry'vors!*

by Rita Banach

As you can see from the look of this newsletter, Canadian Thyroid Cancer Support Group (*Thry'vors*) Inc. has changed its name to Thyroid Cancer Canada!

We thought the new name would better describe our whole mandate, and certainly would be easier to understand.

Fear not. We still refer to our members as thriving, thyroid, survivors... that is, "*Thry'vors*" and this newsletter will continue to be titled *Thry'vors News*.

Along with the official name change, came the need to update many of our services. We are in process of developing a brand new website, new online forum and new publications.

As well, we are going to provide many of our services in the French language for francophone Canadians, who until now, had little support and information in regards to thyroid cancer in their native language. We plan to translate our new website, many of our publications, and provide telephone and email support. If you are bilingual, this is certainly an area that we require volunteer support with.

Our 2010 Annual General Meeting will be our first using our new name. We hope you can join us for this event in Toronto on May 29, 2010. Please contact us to be put on the mailing list for event details or watch the Online Forum for announcements.

Thyroid Cancer Canada (TCC) is also pleased to announce that it has a new Facebook page at Thyroid Cancer Canada. Rita Banach (President) has a Twitter page at mythyroidcancer. Please follow the up-to-date happenings at TCC by one of these online social networks.

For now, our Online Forum remains at its previous site <http://health.groups.yahoo.com/group/Thryvors/> but will be moving soon to a new host. We'll let you know about that change too in our next newsletter.

This is the 26th in a series of seasonal newsletters, from Thyroid Cancer Canada. Your comments and suggestions are most welcome.

Please direct your comments to the Newsletter Committee at thryvors@sympatico.ca

Editor's Note:

Thry'vors News welcomes 2010 with many new changes – including a new name! We have recently changed our name to Thyroid Cancer Canada. With other exciting projects in the works, including a new website and in-person peer support groups, it's shaping up to be an eventful year. Well done TCC!

Sarah Lyons, MA *Editor*

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Offering information and support



Thyroid Cancer Canada Peer Support

Exciting news for Spring 2010!

Thyroid Cancer Canada (TCC) is pleased to announce the launch of two face-to-face peer support groups. This is an exciting new project for TCC, one that we are hoping to expand to reach our members across Canada. Initial plans are to launch the first two groups in the Toronto and Mississauga/Brampton areas.

Our peer support groups will meet monthly, providing our members, their families, and friends with a safe and supportive space to share their experiences. These meetings will be organized by trained TCC peer support facilitators.

Are you interested in attending or learning more about TCC face-to-face peer support groups? Please email us at thryvors@sympatico.ca to inquire about groups in your area.



Mearl and Mary Van Diepenbos

Mary lives in a town outside of Grand Rapids, Michigan. On the same morning she received the envelope of printed matter from the cancer society, she noticed another lump on her neck.

Mary said, "I tore open the package and read: 'There are four types of thyroid cancer.' I ticked them off as I read each description: Follicular – no, that didn't fit; Papillary – no, that one either; Medullary – not that one; Anaplastic – yes! I couldn't believe what I read: 'Does not respond well to treatment. Most patients die within six months.' We were numb. We were prepared for cancer, but not this."

It is said that thyroid cancer is a form of cancer with the largest range of outcomes, based on the type diagnosed. That is, Papillary type (the most common type) has a near 100% survival rate for the majority of patients. Whereas, the very rare Anaplastic type is completely at the other end of the spectrum. Normally this type spreads rapidly and is very hard to treat. Although sharing some characteristics with papillary disease, it is thought to develop from an existing follicular cancer that further mutated, that is, became undifferentiated over time. It is believed that Anaplastic cancers are likely long existing tumours that were left untreated and suddenly became aggressive. The mechanism that makes tumours switch to this type is not currently known. About 1.5% of cases are Anaplastic.

Mary and her husband soon had the follow-up appointment with the surgeon who confirmed that she did in fact have the Anaplastic form of thyroid cancer. The initial tumour and three lymph nodes removed were positive for the disease. He assured them that the new lump was an abscess from the surgery and he scheduled an appointment with radiology for external beam radiation treatment.

A week later Mary had two more lumps. The surgeon had another look and made a phone call to assure that radiation treatment could begin the following day. An ultrasound appointment also confirmed that all three new lumps were indeed new tumours.

Mary had four weeks of external beam radiation including all parts of her neck and upper chest. This was followed with two weeks of high-energy linear acceleration electron

Thriving Thry'vors

Mary's Amazing Recovery from Anaplastic Thyroid Cancer

by Rita Banach

I had the pleasure of meeting Mary, a woman with the Anaplastic form of thyroid cancer, at the 2009 ThyCa conference in Boston. Using Mary's own words, it is my pleasure to tell the story of her thyroid cancer journey with amazement and congratulations and most of all – as a testament to the fact that we all have the ability to survive and thrive even with the worst (or so we are told) of circumstances.

Mary Van Diepenbos' thyroid cancer journey story begins in much the same way as it did for many of us. On Boxing Day 1994, when Mary was 56 years old, she noticed a lump on her neck. Two weeks later, she had a neck dissection to remove a large tumour and three lymph nodes. A few days after that she was told by phone that the pathology was positive for thyroid cancer.

Once Mary got that phone call she contacted the American Cancer Society for a package of information,

radiation. According to the National Cancer Institute, the stream of radiation produced via electron linear accelerators damages the genetic material of the cancer cells, rendering them unable to continue dividing.

“It wasn’t long before the radiation took its toll. I was very tired, sleeping about 16 hours a day. I had a hard time swallowing and keeping food down. My salivary glands dried up. I carried a water bottle everywhere I went.”

That very low point also seemed to be the turning point. One day Mary had the thought that the tumours seemed to be shrinking a bit. Her doctor had the same thought. The surgeon confirmed that the central mass was gone. “He said, ‘In my years of practice I have seen two or three cases that are really miracles; and you are one of those.’”

Mary’s next visit was to a medical oncologist who suggested that she would certainly require chemotherapy once the tumours started to grow again. He’d wait for evidence for that change in condition.

He’s still waiting!

On the 4th of July, 1995, Mary and her family celebrated the 6 month point. They beat the mortality statistic and passed that significant milestone. The following month her doctor made it official and told her she was in remission.

It took a full three years for Mary to feel she had her stamina back after the aggressive treatment she had received. At that point she asked whether she should have a thyroidectomy as her initial surgery only removed the metastatic tumor. The oncologist advised her not to as she would have a great deal of scar tissue from the previous surgery and radiation.

At Mary’s five year anniversary appointment her doctor informed her that so few people get to this point with Anaplastic thyroid cancer, there was no protocol for follow-up. She was scheduled for a one-year follow-up.

In January 2001, Mary’s family doctor wanted to drop the dosage of her thyroid replacement hormone. She’d been on a very suppressive dose to help keep the cancer under control. When he explained his rationale for reducing her dose, it sounded reasonable. He lowered the dose again in February. But, when he suggested in April that he lower it still more, Mary said no. She felt this may not be a wise course of action for her and “had visions of the lowered dosage freeing every one of those little cancer guys to run

all over my body and do their thing again.” Instead she contacted a well-known endocrinologist who specialized in thyroid cancer. He studied all her medical reports and agreed to take her on as a patient.

In September 2001, Mary saw her new specialist. He was interested in the fact that she’d had a lot of treatment, but none of it was conventional for the primary source of the problem, that is, her thyroid gland. She’d had a CT scan and ultrasound test, neither of which was able to find evidence of a thyroid gland, thus some had presumed she no longer had one due to the aggressive radiation she received. Nevertheless, the new doctor ordered a test dose of radioactive iodine treatment (RAI) in order to conduct a Whole Body Scan. The scan did in fact indicate that she still had a wafer thin thyroid gland -- the size of a lima bean.

Back to square one. Mary then had very successful thyroidectomy surgery with a new surgeon. The pathology report indicated no evidence of cancer in the thyroid gland or the lymph nodes around it.

Finally in early April 2002, Mary had RAI treatment to ablate any remaining thyroid tissue. Almost seven years had passed since the time of her diagnosis, yet this was her first treatment dose of this type. In October she had a follow-up scan that was negative for any remnant or recurrent tissue.

Mary says “It’s been 15 years since I was diagnosed with thyroid cancer. I am considered ‘cured’ of the Anaplastic cancer – I’m not dead. In the last seven years I have been monitored with various CT scans, PET scans, bone scans and ultrasounds. My blood work continues to show Tg antibodies, an indication that something microscopic is still lurking. Taking my daily Levoxyl tablet is a constant reminder that I’m living with a chronic disease. So though I am a long-term survivor, follow-up and awareness are still a way of life.”

Note: Mary’s pathology report following her 1995 surgery was prepared by the director of pathology at her hospital in Grand Rapids Michigan, and the diagnosis was confirmed by consultation with the Mayo Clinic. In 2001, Mary’s slides were re-examined once more and the microscopic description again confirms a diagnosis of Anaplastic thyroid cancer.

For more information about Anaplastic Thyroid Cancer see:

Anaplastic Thyroid Cancer and Primary Thyroid Lymphoma: A Review of These Rare Thyroid Malignancies; Green, L.D.; Mack, L.; Pasiaka, J.L.; *Journal of Surgical Oncology* 2006; 94:725–736

MARY'S ADVICE**Mary's Advice for Coping with Thyroid Cancer**

One important lesson I learned is that having cancer is not a passive ordeal. There are plenty of things you can do to not only help you get through it, but also help you to be pleasant through it.

- Learn as much as possible about your type of cancer, so you can make an informed decision. Keep asking questions until you understand and get the answers you need.
 - If need be, get a second opinion.
 - Ask for copies of the test results. You may not understand all the implications, but you may pick up on some key phrases that help in sorting everything through.
 - Keep a journal of medical visits, treatments and phone conversations. It will help you keep track of which doctor said what when.
 - Have someone with you at all your doctor visits. Two sets of ears are better than one; what one misses the other may pick up. The person who goes with you can act as a scribe too, taking notes on what is discussed. It will also give you someone with whom to talk things through afterward who knows what the conversation was. Verbalizing your thoughts helps you sort them out and put them in the proper perspective.
 - Let people know!! They cannot respond if they aren't aware of what's going on.
 - Some of the things you will have to go through may be very unpleasant. That is not a license for you to be rude to your caregivers. They are all on your side (and this includes the medical people) to help you fight this cancer that has invaded your body.
 - Get enough rest. Some days that may be your full-time job. Tiredness is a natural way for your body to let you know it's so busy working on the healing process; it doesn't have time for anything else.
- Admit your emotions. This is a time when journaling is helpful; putting it on paper helps to sort through the various feelings whirling around in your head. Once they are identified they can be addressed. Allow for emotional swings. Mourn what you've lost.
 - Accept help. Gracious receiving is a gift. It's one we too often haven't cultivated. Accept each offering as it is intended. There will be some very inappropriate gestures; however, they are much better than if the person had not tried at all.
 - Express gratitude. Being aware of and acknowledging all the kindnesses, big or small, shown to you will give you a measure of pleasure no matter what you are going through at the time. It will make you aware that not all of life is bad.
 - Count your blessings. They are there and making a conscious effort to be aware of them will be a blessing in itself.
 - Laugh. Laughter is such a great safety valve.
 - Use the arts. Listen to music or literature you enjoy. If you are of a creative bent, express yourself in that way. It's helpful in finding a way to express the things going on in your life.
 - Make time for meditation and receive support via your religious beliefs.



Ask Thry'vors

by Mia Guilló

In This Issue:

We ask two questions. The first, whether thyroidectomies are recommended for teenagers if their Fine Needle Aspiration (FNA) biopsy results are 'indeterminate'. Then we explore whether neck massages are harmful to thyroid cancer patients.

Members of the Medical Advisory Panel of Thyroid Cancer Canada (Dr. Shereen Ezzat and Dr. Alice Y.Y. Cheng) respond to the following inquiries from patient-members of TCC.

Q1 – Thyroidectomy in Young People

If a teenager has a nodule on one or both lobes of the thyroid greater in size than 2cm and if a FNAB comes back 'indeterminate', would you recommend a total thyroidectomy? How is the situation different, if at all, for teens with nodules as compared to adults?

A1 (by Dr. Shereen Ezzat):

A solid thyroid nodule of 2cms or more is of concern and particularly in a teenager. Benign causes of thyroid nodule formation typically present during adult years. Conversely, the presence of a significant thyroid nodule in a teenager who grew up with sufficient iodine in their diet raises questions about its nature. It should definitely be aspirated for cell examination so that a decision regarding surgical removal can be made.

A2 (by Dr. Alice Y.Y. Cheng):

Yes, I would suggest a total thyroidectomy. Age is an important risk factor for thyroid malignancy such that young patients (<20 yrs) and older patients (>60 yrs) have a higher risk of a nodule being malignant. In addition, an indeterminate FNAB result suggests that the cells seen were not obviously benign (and not obviously malignant) and therefore, the level of suspicion is high enough to warrant a total thyroidectomy.

Q2 – Neck Massages:

Can deep massage release cancer cells? Is there evidence to suggest that if there is active cancer, it is important to avoid deep tissue massage to the affected area? Specifically, is it okay for thyroid cancer patients to have their necks massaged either with or without known disease?

A1 (by Dr. Shereen Ezzat):

There is no reason to believe nor is there direct evidence that massage will affect cancer cell growth.

A2 (by Dr. Alice Y.Y. Cheng):

There is no evidence that deep massage can release cancer cells. Patients with or without thyroid cancer can safely undergo deep massage of the neck if needed for other reasons.

Special thanks to Dr. Shereen Ezzat, Professor of Medicine & Oncology Head in Endocrine Oncology at Mount Sinai & Princess Margaret Hospitals as well as Dr. Alice Y.Y. Cheng, Endocrinology and Metabolism Assistant Professor (Adjunct) at the University of Toronto for their assistance with these questions.

POEM

Ode to Gordon

by: Janice Veri

You have grown inside me
several years – not long
No time to investigate
Just procrastinate –
ignoring your potential

I have christened
your importance to me
– more fool, me –
your betrayal now
changes my life

Ironic fate being born
in the sign of the Crab
- you are the Crab-
They will excise you
but can I live without you?

Will I celebrate your death-
or have you authored mine?
I fear the unknown,
-no turning back
I fear who will replace you

**TCC welcomes you to send your poetry to
www.thryvors.org**

Thyroid Cancer Canada Volunteer Opportunities

by Nancy Brouillard

Exciting opportunities to suit every need! Learn more about special event planning, community networking, public speaking and much more!

Volunteers are needed across Canada to lead and motivate the following: Fundraising; Ambassadors; Communication and Media Relations; Newsletter writers/proof readers; Marketing and Public Relations; Francophone support and Volunteer Development.

If you thrive on...

- building teams and working with others
- leading and coaching
- achieving results

you may find that a 'Chair' role is the right fit for you. Time commitment varies depending on the portfolio, so there's sure to be something to match your availability, skills and experience.

Administration/Health Promotion/Volunteer Support

Administrative volunteers keep our fundraising, health promotion, distribution, representation, education and volunteer development programs running smoothly. We are looking for volunteers to support a variety of tasks that will assist in raising awareness of Thyroid Cancer Canada and the supports that we provide.

Public Speakers and Ambassadors

Volunteers provide information directly to the community on important topics related to Thyroid Cancer and are provided with the information and tools necessary to deliver presentations in a variety of settings. Want to help but don't like public speaking? Talk to us about becoming a Thyroid Cancer Canada Ambassador. Ambassadors deliver Thyroid Cancer Canada materials to local health care professionals.

Fundraising Support

Thyroid Cancer Canada receives no Government support and relies completely on private and corporate donations and grants in order to produce our printed materials, and support to those living with Thyroid Cancer.



We are always in search of volunteers to help to develop fundraising programs and events, to help provide sales, marketing and customer service support.

Volunteer Development Support

We are a completely volunteer-run, non-profit organization. Volunteers sustain this invaluable organization by taking active roles in the recruitment, orientation/training and recognition of their fellow volunteers.

Are you...

- able to effectively develop people and build teams?
- knowledgeable about recruiting, training, and/or recognition?
- good at facilitating and presenting?

then consider a role in volunteer development!

Occasional Support

Thyroid Cancer Canada has a need for volunteers who are available for one or two days at various times during the year. These roles can range from a day at a fellow volunteer's house stuffing envelopes, to helping at a Patient Forum, or volunteering at events. We are also looking for volunteers to distribute materials to their health care professionals, workplace, schools, etc. in order to raise awareness of Thyroid Cancer Canada and the supports that we provide. If you are available to help out for any of these occasional or short term assignments, please contact us to have your name added to our list of Occasional Support Volunteers.

We welcome all volunteers in any capacity. To offer your assistance with any of the above tasks or others, contact TCC at thryvors@sympatico.ca or 416-487-8267

The Best Ways to Cook Vegetables

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 Thryvors News.

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

Jimenez-Monreal AM, Garcia-Diz L, Martinez-Tome M, Mariscal M, and Murcia MA. (2009) Influence of Cooking Methods on Antioxidant Activity of Vegetables, *Journal of Food Science*, 74(3): H97-H103.

Main Message:

Diets high in vegetables have been associated with a reduced risk of some cancers. One of the reasons for this is because they contain a lot of nutritional and non-nutritional antioxidants.

What was the research question?

Vegetables are typically eaten after being cooked which is thought to alter the cancer protecting qualities of vegetables. The researchers were interested in exploring what happens to the antioxidant activity or free radical capacity of vegetables (in other words their cancer protecting qualities) during cooking. This article attempts to find out the best cooking methods in order to preserve the cancer protective qualities of vegetables.

How was the research conducted?

Spanish researchers tested 20 vegetables (artichoke, asparagus, beetroot, broad bean, broccoli, brussels sprout, carrot, cauliflower, celery, eggplant, garlic, green bean, leek, corn, onion, pea, green pepper, spinach, swiss chard and zucchini) in their food science laboratory.

Using the exact same method for each sample, vegetables were cleaned,

washed, cut and cooked in six different ways (boiling, microwaving, pressure-cooking, frying, griddling and baking) and then measured for cancer protective qualities. As there is no simple universal method to accurately measure for cancer protective qualities (free radical scavenging and antioxidant capacity), the researchers applied three different chemical methods to all samples.

What were some research findings?

When vegetables are cooked they will retain a portion of their cancer protective characteristics, depending on which vegetable it is, how it's cooked, and other chemical factors. In some instances, cooking improves these characteristics but it is not clear why this occurs.

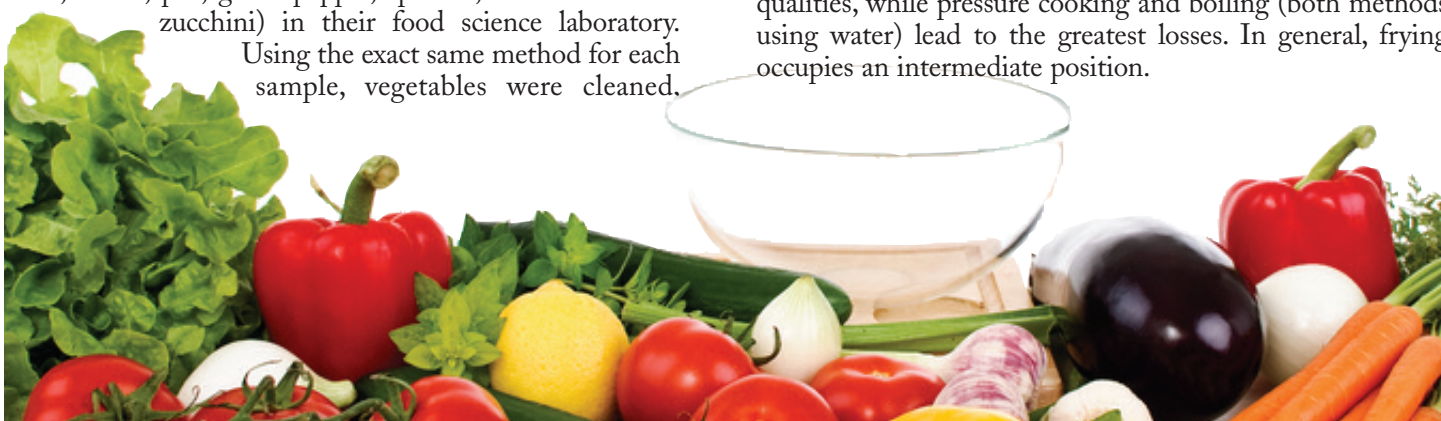
In the first test, artichoke was the only vegetable of those analyzed that kept its very high anti-cancer qualities in all of the cooking methods. The highest losses were observed in cauliflower after boiling and microwaving; in peas after boiling; and in zucchini after boiling and frying.

In the second test, beetroot, green bean and garlic kept their antioxidant activity after most cooking methods. Swiss chard and pepper lost some cancer protective qualities in all processes. Celery increased its anti-cancer properties in all cooking methods except boiling.

In the third test, the highest losses were in garlic using all cooking methods except in microwaving, which produced a very large loss in corn. Zucchini showed loss after boiling; swiss chard, corn, leek and zucchini showed loss after pressure-cooking. Green bean, celery and carrot increased their values after all cooking methods.

What were the final recommendations?

Depending on the vegetable, griddling (cooking vegetable in a thick frying pan with no oil) and microwave cooking (cooking vegetable in a glass dish without water in a microwave) produced the lowest losses in cancer protective qualities, while pressure cooking and boiling (both methods using water) lead to the greatest losses. In general, frying occupies an intermediate position.



LID RECIPE BOX**Matzoh* French Toast**

From KatieKabob

- matzoh
- egg whites (or substitute)
- non soy oil

Brake matzo into quarters.

Place under warm water for 10 seconds.

Then, like with French toast, place matzoh in egg whites. Let it soften up for a while, then place in oiled frying pan. Serve with powdered sugar, cinnamon.



* Matzoh is a type of large square cracker, packaged in small boxes. The plain variety of this type of cracker has only 2 ingredients – flour and water, and is therefore a good bread-substitute for those on the Low Iodine Diet. Matzoh crackers (also spelled Matza or Matzo) are usually stored in the special foods or ethnic foods section of the supermarket.

New Recipes are continuously added to the *Thry'vors* LID Recipe Index - now including almost 400. To view LID recipes, go to: <http://health.groups.yahoo.com/group/Thryvors> or view a sampling of recipes at www.thryvors.org

Upcoming Events**Hold This Date:**

Thyroid Cancer Canada's Annual General Meeting

To be held on May 29, 2010

Location: Greater Toronto Area

Details available by May 1, 2010

Events from the Community**Cancer Prevention Awareness Day.**

March 26, 2010

In a joint initiative with Go Public, and CPOOnline, the School of Health and Human Performance at Dalhousie University is pleased to welcome Mr. Stephen Lewis (former United Nations ambassador and special envoy for HIV/AIDS in Africa). Mr. Lewis will speak to the importance of cancer prevention and awareness to the Dalhousie community. The daylong event will also include other activities. For more information contact Lynne M. Robinson, PhD, RPsych 902.494-1157 lynne.robinson@dal.ca

Retreat Yourself – A Free Retreat for Young Adult Cancer Patients/Survivors

May 27-31st, 2010 in Vancouver, BC

Retreat Yourself is FREE to young adult patients/survivors who have been diagnosed, and who are currently, between the ages of 18 & 35ish, and one supporter (but no parents). The dates are set for our next retreat and registrations are now open.

Retreat Yourself will be taking place just outside Vancouver, BC. Although the retreat is free for survivors and their supporter they are responsible for their travel to and from Vancouver. We know that this is often very difficult, especially for young adults, so to ease the financial burden of travel YACC has a travel subsidy fund for retreaters, based on their home province. Young Adult Cancer Canada is willing to assist young adults in raising the travel funds and has a fundraising model that they may find helpful.

Please click the following link to view a video promo and find out more information regarding Retreat Yourself: www.youngadultcancer.ca/retreat_yourself/

If you have any questions regarding Retreat Yourself or any of the YACC programs contact Karine Chalifour, Program Director karine@youngadultcancer.ca

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.

Donation cheques can be made payable to: Thyroid Cancer Canada

Mail to: Thyroid Cancer Canada

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