



Thry'vors News

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Autumn 2006

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This is the 12th 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 Newsletter Committee at thryvors@sympatico.ca

A Word from the President

The spring was a busy time for Thry'vors. We held both a Volunteers' Day and our Annual General Meeting.

The Volunteers' Day, held in early April, brought together those members who wanted to learn more about our charitable organization and the various openings we have for needed assistance. Current volunteers met with our newest members, in the beautiful setting of Hillside Outdoor School in the Rouge Park, Scarborough. The day was split between working sessions and relaxation time. We enjoyed such activities as a one hour meditation session, chickadee hand-feeding in the Rouge Valley and a marshmallow roast. Several within the group of 22 attendees, came forward to help out as committee chairs or members.



Chickadee feeding in the Rouge Valley

Amongst the activities of Volunteers' Day, was a recognition ceremony for several of our long-time, dedicated volunteers. We acknowledged the contributions made by: Rita Banach, Ann Dreger, Lynda Murtha, Melissa Pecile, Jasna Schwind, and Grace Wright. Each of these volunteers received a lapel pin in Thry'vors colours signifying our great appreciation for all they do to support the group.

In all, it was a very successful day and one I hope we repeat annually.



The focus of this issue of the Thry'vors News is

on topics of interest to teens and young adults diagnosed with thyroid cancer. Many of thyroid cancer survivors are in this age group, yet their unique needs for information are rarely recognized. We are trying to address this oversight. Inside this newsletter you will find answers to questions provided by Thry'vors members. We hope you enjoy this edition of Thry'vors news. Andrea Peca and Tara Gallagher, Co-editors.

www.thryvors.org

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Offering information and support



A Word from the President *continued*

At the end of May we welcomed 22 members to our Annual General Meeting, held at Mt. Sinai Hospital, Toronto. Highlights of the afternoon activities included an information session with representatives of manufacturer of Thyrogen®, the election of our new Board of Directors, the President's Report outlining the activities of the group in 2005-2006, and an open discussion of various topics including finding new ways of encouraging members to make donations, a discussion of "neck-checks", and promoting good eating through various "Field to Table" programs.

We also welcomed 15 committee chairs who will help coordinate the various important activities that Thry'vors undertakes each year. These include coordination of the listserv, website, volunteers, liaison to our medical panel, distribution of printed matter, and much more. Two of our committees are without chairs currently (i.e. fundraising and media) and we welcome you to contact us if you'd like more information about volunteering for Thry'vors in these important positions, or as committee members. As well, you are welcomed to contact me should you like a copy of the minutes from the AGM.

The over 30 volunteers who commit their time to our organization come from all walks of life, and every part of Canada. Although their backgrounds are quite diverse, they all hold in common the desire to create a supportive and informative environment for those affected by thyroid cancer. I thank all our treasured volunteers for their hard work and devotion to our cause.

Rita Banach B.Sc. D.C.S.

President

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The 2006-2007 Board of Directors of Thry'vors are:

Rita Banach	President
Jasna Schwind	Vice-President
Grace Wright	Secretary-Treasurer
Myra Fan	Director
Nola Goertz	Director
Tara Gallagher	Director
Andrea Peca	Director
Melissa Pecile	Director
Beth Rajnovich	Director



Some of the gang at Hillside Outdoor School

Accessorize...and help others access support



Through your financial support of Thry'vors, you help to ensure that individuals across Canada can access our educational material and support resources as they cope with the challenges of thyroid cancer.



Receive a gift for every tax receiptable donation of \$50.00
we will send you your choice of the "Pearls of Wisdom" necklace or the butterfly Swarovski crystal earrings.

To make a donation or to find out more about this offer please visit www.thryvors.org



Lauren's Story... A Mother's Journey

By: Stephanie Carper

Each year I take my children for a routine physical and 2004 was no different. The very instant Dr. Cook felt Lauren's neck I could tell something was wrong. Lauren was referred for a thyroid ultrasound after her brand new paediatrician felt a suspicious mass on the right side of her neck. I felt numb as the technician did the ultrasound, especially when she kept taking measurements. She had us wait in the office until she spoke with the radiologist. By the time we returned home, I had specialists from Children's Hospital calling to get Lauren seen the next day. I could hardly breathe and I knew something was terribly wrong. A mother just knows.

The day after Thanksgiving 2004, surgery to remove the tumor confirmed the cancer diagnosis. Two weeks later she underwent a total thyroidectomy. I had never heard of anyone with thyroid cancer and suddenly I was hearing words like "thyroglobulin" and "radioactive iodine." The world as I knew it for the last 13 years had changed forever. My child had no symptoms when she went for her check-up and suddenly she was a cancer patient.

In January 2005, Lauren underwent I-131 radiolabeled iodine ablation after receiving two injections of Thyrogen and numerous scans. I watched as Lauren had to drink the radiation through a straw from a large metal container. The staff took many precautions from exposure, yet there stood my baby full of radioactive material. As mothers, we try to protect our children from the things that harm them, but strangely enough the very thing that caused her cancer may also help cure her.

For the next week or so Lauren was in isolation at home. This is how she spent her Christmas holidays. Alone. We followed the protocol as much as possible, although very difficult, especially for a child. Her clothes and linens were washed separately, no one could use the bathroom after her, she used plastic utensils and had to limit contact with the rest of the family and pets.

Every since the initial diagnosis I was told how thyroid cancer was rare in children and how it was the "best" cancer to have since the survival rates are nearly 100 percent. I had



read that there are only about 300 new cases of thyroid cancer diagnosed in the U.S. yearly in teenage children. I had also read that the type of cancer Lauren had was caused by exposure to large amounts of radiation. But where?

Upon returning to school in January, Lauren was overheard talking by a young man named Bryce whose locker was just a few down from Lauren's. He asked Lauren about her surgery and testing then discovered they were being treated for the same disease. The kids exchanged phone numbers so their mom's could talk. My heart sank when Debbie called me and confirmed that Bryce had the same cancer as Lauren. Within weeks we learned of yet another case of thyroid cancer in our schools. We were finally able to connect with Missy to confirm what we had heard. It was true, 17 year-old Amber had thyroid cancer too. In our small community of 11,000 there were now three confirmed cases of thyroid carcinoma in our teens. All three kids have attended the same school and live within a mile of each other.

Since January Lauren has had numerous doctor's visits, blood tests, MRI's, PET scans and CT scans. I can't count the number of times we've been to Children's Hospital or the number of times she's been poked with a needle. But I do know how many times she has complained. NEVER! Although we have shed our fair share of tears, Lauren has never been negative or complained about anything. Her smile lets me know that everything is going to be okay. Lauren is currently being monitored for a suspicious mass in between her carotid artery and windpipe. She is a 9th grade honor roll student at Edgewood High School and is active in Girl Scouts and dance. She enjoys puzzles, babysitting, shopping and her friends.

Everyone says things happen for a reason. Although I'm not quite sure why these kids were chosen to get this disease, I do know that through all the tears and questions, I have gained two wonderful friends who have helped me through the hardest time of my life. I believe support is so important when dealing with a crisis such as cancer, especially with our children.



Recipe Box

Citrus Muffins

3/4 cup non soy vegetable oil
 1 cup sugar
 3 egg whites *
 1-1/2 cups flour
 1 teaspoon non iodized salt
 1 teaspoon baking soda
 1 teaspoon vanilla
 1/4 cup fresh citrus juice
 2 tablespoons grated citrus rind

Line muffin pan with paper liners.
 Combine oil, sugar, and egg whites. Mix well.
 Add remaining ingredients and blend.
 Pour into muffin pan. Bake at 350 F for 10 - 15 minutes

* if using egg substitute, use equivalent of 2 eggs

Smoothies

Berry Blaster

½ cup frozen blueberries
 ½ cup strawberries
 Pour in enough juice or herbal tea (cranberry, orange, berry, hibiscus) to cover the fruit
 add a teaspoon of honey (optional)
 add a teaspoon of flax oil (optional)
 drop of vanilla (optional)

Puree in a blender until smooth.



New Recipes Added to the Thry'vors LID Recipe Index

Our Thry'vors index contains over 230 recipes. To view LID recipes, go to:
www.groups.yahoo.com/group/thryvors/files

Please post your favourite recipes to the listserv and they will be added to our index.

From a Survivor's Point of View

By: Andrea Peca

Cancer affects many people. It does not care who you are, or how old you are. It does not pay any attention to whether or not it is the right time to enter your life. It does not care how healthy you are or how sick you will become. It does not mind if you will suffer any financial burden.

Cancer creeps into our lives suddenly, and there is no true understanding of why you were chosen. But one thing is true, cancer will become you. It is the responsibility of the cancer survivor to encourage others to become aware of changes in their body. Cancer cannot necessarily be prevented but early detection will benefit the quality of life.

Become aware and continue to promote awareness. Be a cancer survivor not a cancer victim.



Ask Thry'vors - QUESTIONS ABOUT TEENS AND THYROID CANCER

Special Thanks to:

Dr. Driedger

Professor of Nuclear Medicine/Oncology, University of Western Ontario, Acting Chief of Nuclear Medicine, London Health Sciences

Q. Are more teens and young adults being diagnosed with thyroid cancer? Do you think there is a link between the number of xrays young kids are exposed to these days? I am amazed at how many young people are finding themselves having thyroid cancer. There really must be something wrong with our environment. Since my thyroid cancer I have become more aware of how many xrays my kids are getting at the dentist. I noticed that the lead vest do not cover their necks but only their chest.

Can thyroid cancer be prevented? How?

A. One known cause of thyroid cancer is radiation at fairly high doses. For instance, in the 20 years since the Chernobyl accident there have been about 4000 cases of thyroid cancer in the area of contamination. In principle, we think that low doses may cause a small number of cancers, but in studies the number of cases so caused is too few to be detected as an increase above the natural incidence.

The incidence of thyroid cancer has been increasing for several decades and for reasons we don't understand. The increases are happening in countries that don't have access to dental and medical xrays as well as in those that do. If radiation is a factor, then we would expect to find a higher incidence in regions with a higher natural level of radiation: the problem is we don't see that.

Thyroid cancers are common in young people, especially in girls. So, we can guess that there is a hormonal effect that moderates thyroid cancer expression.

There is a genetic factor. We see a family incidence in about 6-8 percent of cases.

I can't tell you how to prevent thyroid cancer because we do not know all the causes.

Wonder by Janice Veri

The radiation in my head
Has changed my sight
No longer black and white
I see colourful hues

What irony- this force
Is used to kill and maim
Yet heal the sick-
Where lays the decision?

My brain now teems with words
Never stopping- filling
Each moment with
New perspectives of life

Each scent more fragrant
Each colour vivid
Etching imprints-
Indelible in my mind

The wonder I feel
Is bursting inside
This second life
I have been blessed to live

**Send us your poems.
Email thryvors@sympatico.ca**

www.thryvors.org

Thry'vors needs your help to make others aware of our support group. If you are willing to tell your doctor, clinic, cancer treatment centre, pharmacy, public library, employee services department, or any other organization about Thry'vors, please e-mail us at thryvors@sympatico.ca and we will send you samples of our brochure, patient booklet and an order sheet to bring to your doctor/facility. Our members are our very best promoters!

Offering information and support





Ask Thry'vors - QUESTIONS ABOUT FERTILITY AND PREGNANCY AFTER THYROID CANCER TREATMENT

With special thanks to:

Dr. Shereen Ezzat,
Director, Freeman Centre for Endocrine Oncology Mount Sinai Hospital, Professor of Medicine, University of Toronto, and member of Thry'vors Medical Advisory Panel

Dr. Denice Feig,
Endocrinologist, Mount Sinai Hospital and Associate Professor at University of Toronto

A) BEFORE GETTING PREGNANT

Q. What is the effect of RAI on a woman's fertility?

A. There appears to be no harmful impact of radioiodine therapy on a woman's fertility, with the exception of one study which found a small increase in the rate of miscarriages in women who became pregnant during the first year post therapy. Other studies, however, have not confirmed this finding. Whether the increased incidence of miscarriages within the first year relates to gonadal irradiation or to insufficient control of hormonal thyroid status is still not known.

Q. What is the effect of RAI on a man's fertility?

A. Oligospermia (low sperm count) may occur transiently, but long-term male infertility is rare except after high doses.

Q. How long should a woman wait to get pregnant after RAI therapy?

A. It is recommended that women wait approximately 1 year after radioiodine therapy before becoming pregnant. This recommendation likely stems from the study which showed an increased incidence of miscarriage during the first year after RAI therapy and the concern that persist-

ent effects of radiation MAY cause cytogenetic damage for several months. Waiting one year will also give the physician time to investigate whether the cancer is no longer present, and will allow the patient's thyroid status to be adjusted to the appropriate level. Other studies, however, have not found an increase in miscarriages or adverse neonatal outcomes in women who received iodine therapy within the first year.

Q. How long should a man wait to conceive a child after RAI therapy?

A. One study of men who had received radioiodine for thyroid cancer, there was a transient elevation in serum FSH after radioiodine which normalized within 9 months from the last administration. They concluded that radioiodine treatment may result in transient impairment of gonadal function, but the risk of infertility in these patients is minimal. Patients requiring multiple administrations for persistent or metastatic thyroid cancer may be at greater risk of gonadal damage, although even in this group they found no evidence of infertility.

B) EARLY PREGNANCY

Q. In a patient who has undergone RAI therapy for thyroid cancer, is there an increased risk of genetic and chromosomal abnormalities to the children?

A. No. Genetic and chromosomal abnormalities due to exposure to ¹³¹I probably occur in only one percent of live births after a cumulative dose of 500 mCi (18500 MBq), and even less frequently after lower doses. (The average dose given to ablate the thyroid after total thyroidectomy for thyroid cancer is 100 mCi).

Q. If a patient is discovered to have thyroid cancer during pregnancy, is it safe to wait for surgery?



A. If a woman is discovered to have well-differentiated thyroid cancer during the first trimester, she may elect to have the surgery done during the second trimester. The risk of miscarriage during the second trimester from surgery is quite low. However, if she chooses not to have surgery during the second trimester, or is discovered to have thyroid cancer during the third trimester, there is no evidence (except for one case described) that the delay results in a worse outcome.

Q. If a patient has surgery for thyroid cancer, but discovers she is pregnant prior to receiving the RAI, is there a risk to delaying the RAI?

A. Studies show there is no risk to delaying the initial surgery and RAI that follows, so one would assume that there is no risk delaying the RAI till after delivery.

Q. Is there a risk to receiving the RAI during pregnancy?

A. Pregnancy is an absolute contraindication to radioiodine therapy. Fetal thyroid tissue concentrates iodine after the eighth week of gestation and would be destroyed by the radioiodine, resulting in cretinism.

Q. If a patient is discovered to have thyroid cancer during pregnancy, are there risks of thyroid cancer to the fetus?

A. In most cases the answer would be no. Familial (genetically inherited) well-differentiated thyroid cancer is very rare.

Q. Can pregnancy trigger thyroid cancer or increase the chances or recurrence?

A. Aside from the occasional report suggesting pregnancy may lead to an increased growth of thyroid cancer because of the elevated HCG (human chorionic gonadotropin) which acts like TSH to increase thyroid production, most studies suggest that pregnancy does not affect the course of thyroid cancer.

Q. If a patient is on thyroid hormone replacement, why do the levels need to be followed in pregnancy?

A. During pregnancy there is an increased demand for thyroid hormone. This is because of an increase in thyroid binding globulin which binds free thyroid hormone, and because of increased clearance of iodine. For these reasons, the dose of thyroid hormone needs to be increased, or the woman may potentially become hypothyroid. The fetus is not fully able to make thyroid hormone until 18-20 weeks gestation, so it is dependent on the mother for thyroid hormone during this time. Some investigators have hypothesized that low levels in the first trimester may translate into developmental problems in the baby. Hypothyroidism, or low levels of T4 in the first trimester have been associated with decreased IQ and developmental abnormalities in some studies. As well, a recent study of women with subclinical hypothyroidism (meaning high TSH, normal free T4) found an increased risk of placental abruption and preterm birth. Maternal hypothyroidism has also been associated with an increased risk of gestational hypertension and preeclampsia. For these reasons, we increase the dose of thyroid hormone in pregnancy, and follow the thyroid function tests in pregnancy. As well, one would want to not only avoid hypothyroidism in a woman with thyroid cancer, but maintain her TSH in the suppressed range. Usually patients are followed every 6-8 weeks until 20 weeks, then every trimester. There is no increased risk to the fetus if a woman has a suppressed TSH, but normal free T4.

Q. Should a patient who is post total thyroidectomy eat or avoid any certain foods while pregnant?

A. No.

Q. How safe is it to stay away from bad carbs while pregnant?

A. A certain amount of carbohydrates (approximately 175g/day) is recommended as part of a healthy diet during pregnancy. One can choose 'healthier' carbs such as those high in fiber.



Q. Are there statistics regarding weight gain for post TT women during pregnancy?

A. Not that I am aware of.



AFTER PREGNANCY-NURSING

Q. Can women safely take thyroid medication while nursing?

A. Yes. Women are usually put back to their pre-pregnancy dose immediately after delivery, and their thyroid function tests are checked 6-8 weeks postpartum.

Q. Is it safe to stop nursing for a few days, have RAI treatment, then resume nursing?

A. It is not safe to resume breastfeeding after RAI treatment as the iodine stays in the mother's body for quite a while.

Tell us what you think

Your comments and suggestions are welcome.

Editors: Andrea Peca, and Tara Gallagher

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(ursula@litmusdesign.ca).

Image source: iStockphoto

litmus DESIGN

Upcoming Events

The 9th International Thyroid Cancer Survivors' Conference.

Sponsored by ThyCa: Thyroid Cancer Survivors' Association, Inc.

DATE: Friday-Sunday, October 27, 28, and 29, 2006.

LOCATION: At the Sheraton World, 10100 International Drive, Orlando, Florida 32821.

The Conference features more than 80 sessions: The latest research, advances in treatment and follow-up, insurance and employment issues, and coping skills for well-being. The more than 50 speakers will include leading physicians and other specialists. The hotel has arranged special room rates for conference attendees for single, double, triple, or quad rooms. Details will continue to be added to the ThyCa web site at www.thyca.org.

ThyCa's 5th Annual Dinner/Auction to Support Research.

DATE: Saturday, October 28, 2006 from 6 p.m. to 10 p.m.

LOCATION: At the Sheraton World, 10100 International Drive, Orlando, Florida 32821.

Sponsored by ThyCa: Thyroid Cancer Survivors' Association, Inc. and held in conjunction with the 9th International Thyroid Cancer Survivors' Conference. Details will continue to be added to the ThyCa web site.

Public Education Meeting

London Area Chapter of the Thyroid Foundation of Canada

DATE: November 21, 2006, 7:30 - 9:00 p.m.

LOCATION: Central London Public Library (address below)

SPEAKER: Dr. Merrill Edmonds, Endocrinologist & Chapter Medical Advisor, St. Joseph's Health Centre

TOPIC: Hypothyroidism

All Public Education Meetings are held at the Central London Public Library in the Stevenson & Hunt Room, 251 Dundas St.

ALL WELCOME! OPEN TO THE PUBLIC! FREE

ADMISSION! For more information call: 519-649-5478

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 Thyrvors.org.

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

Mail to: Canadian Thyroid Cancer Support Group (Thy'vors) Inc.

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