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

Thry'vors News

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This is the 15th 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

Thyroid Cancer and the Male Experience

by: Rita Banach

James Gaulton of Dundas, Ontario is a very rare guy. He has a rare cancer -- and his case is still more unusual as the population of thyroid cancer patients is predominately made up of women. Rare as having thyroid cancer is, his diagnosis and treatment followed a course that is fairly standard. His family doctor noticed a lump in his neck during a regular check-up in 2005. A total thyroidectomy followed, to remove a large 5cm papillary tumour. Only one of his four parathyroid glands could be saved, and thankfully it started functioning within a month post-surgery. James has recently had a 'clean' scan (WBS) as well as further good news from a blood test that measured his stimulated thyroglobulin (Tg) (the cancer marker for thyroid cancer was less than .2 mlU/L.)

Unfortunately, not all men share James' relatively positive experience. It is often the case that men with thyca have a harder time of it for one reason or another. Their general prognosis is not as favourable as it is for women. In 2003, 21% of those diagnosed with thyca were men (Canadian Cancer Society[1]). However, the mortality rate for men is disproportionate. Of the small number of Canadians who died from thyca (150 deaths), 39% were men.

Thankfully, thyca has a great overall survival rate. Eighty-five percent of patients have the differentiated forms of the disease (papillary or follicular) which are very treatable. However, the Canadian Cancer Society (CCS) does not distinguish between the four types of thyca in their statistical analysis. We know that the rare, undifferentiated forms of the disease (medullary and anaplastic) are more aggressive variants. The question remains however, when combining all forms

Thry'vors expresses its sincere appreciation to Andrea Peca and Tara Gallagher who were the co-editors of Thry'vors News in 2006-07. Over the last year, the newsletter received acclaim from our readership in regards to its improved readability and design, as well as its interesting and useful articles. We thank our editors and Ursula Gallagher (the newsletter's layout/designer) for our great little publication.

We welcome Rhonda McMahon as the editor for 2007-08 and look forward to her generous contributions.

www.thryvors.org

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Offering information and support

of thyroid cancer for analysis, the survival rate is 97% for women and only 92% for men.

The gender divide in regards to mortality is reflected in our own membership population. We currently have 471 full members in our database. In recent years we have lost 4 members to thyroid cancer. Three of the 4 deceased were men.

One of those we recently lost was Rob Smith of Duntroon, Ontario. Rob's journey with thyca began in 1996 when he was diagnosed with medullary thyroid cancer (MTC). His wife Jody is a truly remarkable person who participated completely in Rob's fight with the disease. She reports that Rob, an active 52 year old, had many years of relative good health before the cancer started taking its toll last year. Jody "kicked into gear" once Rob's health started deteriorating. She studied MTC so thoroughly that she quickly became very well-informed about the disease. Jody said, when one is diagnosed with MTC, you have to become both knowledgeable and active in your own treatment. She suggests that everyone should become "their own best advocate and take an active role in their health as much as possible. Take it into your own hands" as she put it. She scoured the internet for information and drugs trials and at one point Rob travelled to Detroit to participate in the AMG706 trial. Rob kept his positive outlook and sense of humour throughout his ordeal. Despite their valiant efforts, Rob passed away just after Christmas 2006.

Several questions arise from this. Why is the ratio of women to men diagnosed with thyca so disproportionate at 3:1? Why do men have a more difficult time with it, and why is their prognosis less favourable?

We asked Ian Adam, Radiation Safety Officer at the Institute of Cancer Research in Surrey, England (and member of our Medical Advisory Panel) for his opinion. Ian said that at least some of the differences can be attributed to the behavioral differences between the genders. "Men don't make the best patients. Some hesitate to go to a doctor, while women are in tune with their bodies and use mirrors more. These reasons will affect how early a diagnosis is made." As well, women's lifecycle events (beginning of menstruation, pregnancy and menopause) bring them to a doctor for examination. Men "have no such reasons".

Ian's opinion is supported by research. The U.S. National Cancer Institute's database indicates that while general survival rates for thyca have improved from 1974 to 2001, the rates of finding distant metastases in men (at the time of diagnosis) were more than twice as high as they were in women (9% vs. 4%). Dr. Ernest Mazzaferri (president of the American Thyroid Association) reports that twice as many men die from thyca because they on average, present at an older age and have more advanced tumours.[2] Further, he reports that in a study conducted in France, the proportion of women referred for evaluation of a nodule has increased over the past two decades, whereas it has not for men. In the French study this was attributed to the large number of women being followed regularly for general thyroid disorders, and the "way in which men use the health care system".

Thyroid Cancer Statistics
(Canadian Cancer Society 2007)

- there will be 3,700 new cases this year (2,900 women, 790 men)
- rates are highest in Ontario, Alberta and Quebec
- the rate of increase in incidence has gone up 10.4% in women and 4.9% in men (over the last decade)
- mortality (deaths) have gone down by 1.4% in women, and up by .8% in men
- the five year survival rate is 97% for women and 92% for men
- in women age 20-49, thyca is the second most prevalent cancer at 11% of all cancers (breast cancer is #1 at 36%)

Ian Adam also made the somewhat obvious but not to be overlooked point that "a lot of the reasons for the differences between men and women is because of - the differences between men and women!" Some men feel the need to be the 'tough guy' and prefer to ignore their aches and pains as long as possible.

Scott Hagwood would likely agree with Ian. Scott is the four time National Memory Champion of the U.S.A. His pursuit of becoming a memory maven started when he felt hopelessly incapacitated by 'hypo hell' in preparation for his RAI ablation eight years ago. Scott noted the effects again when he prepared for a scan in 2002. He said "during the preparation of the World Memory Championships in London … I prepared for a marathon event called "hour cards" i.e. how many decks of cards can you memorize in an hour? At the time, I could memorize seven decks in perfect order. Two months later, when I went off my Synthroid for the I-131 diagnostic full body scan, I could not remember seven cards in a row. The experience was fascinating. Of course, my memory recovered but it is a scary feeling during those weeks of hypothyroidism."

Artist: Jonathan Wright
He is a thyca survivor living in Iqaluit, Nunavut with his fiancée Alethea Arnaquq-Baril. Jonathan completed the oil painting while a student at Sheridan College, Toronto

When asked about the 'male' experience with the disease, Scott said "The hardest thing for me to do, from a male perspective, is learning to be dependent on a daily drug (Synthroid) at a relatively young age - 36, and all the regular tests associated with cancer - regular blood work, annual x-rays, etc. I have a fear of needles so all this has taken some resolve."

One study conducted last year in Germany addressed the gender issue head on[3]. They studied 1300 patients and examined whether there is a "sex difference or a gender divide?" The research concluded that there are 3 possible explanations for why men have a harder time with thyca. Two of them we have discussed above - differences in screening (e.g. more women that see their doctors for unrelated reasons and have their necks examined) and the gender differences in behaviour (i.e. women aren't as a reticent to point out physical ailments to their doctors). The German study discounted both of these explanations based the population of patients they studied. Jody Smith would agree. She said that her husband, Rob, went to the doctor immediately after feeling the bump on his neck and had his thyroidectomy within a month after that. Contrary to the generalization, he acted quickly and stayed on top of it, for the next ten years. The suggestion that men don't take their health as seriously as women was not true in Rob's case. Jody reports that "nothing could be further from the truth".

The German study concluded that a third explanation must be examined more closely -- that thyca just behaves more aggressively in men. As well, they suggest that heavy reliance on fine needle biopsy (with its often inconclusive findings) has put off surgery by an average of 28 months in their population, a period of time that allows aggressive tumours to take hold and metastasize. This has an even more negative effect in male thyca as their tumours are larger and more aggressive at diagnosis. There is added relevance for MTC patients, as their cancer grows slowly but has a tendency to metastasize early on. The researchers strongly suggest that calcitonin blood tests be carried out routinely in all persons with thyroid nodules, towards diagnosing MTC at an early, manageable stage.

As one male member of our group said, "my doctor was quite aggressive; he wanted me to have the thyroidectomy tout de suite!"

Still, why do more women get thyca in the first place? Ian Adam postulates that there may be a hint in the fact that the ratio of women to men with thyca is 3:1 from understanding

the basic tenets of genetic theory. The 3:1 ratio is characteristic for second generation mutations. That is, "it's possible that an as-yet unidentified gene mutation linked to thyca is found on the X chromosome, and that anyone possessing the male Y is protected to some degree." For example, studies of genes BRAF, BRCA1 and BRCA2 have been linked to a range of cancers. As well, there is clear evidence that 3 out of 4 forms of MTC are inherited (MEN-2A, MEN-2B, and Familial). However, 75% of those with MTC have the "Sporadic" type (not known to be inherited), as did Rob Smith.

The gender difference is therefore a double-edged sword. For women, they are more likely to get thyca but on average it will be at an earlier stage with a good outcome. For men however, while they are much less likely to get the disease, theirs may be more advanced at diagnosis or act more aggressively.

In writing this article, it was heartening to know that men like James Gaulton and Scott Hagwood are doing just as well as their female counterparts. Despite the ordeal of thyca, Scott said "I am just grateful for the experience of thyroid cancer. The experience has changed my life so many extraordinary ways." And remarkably, despite the loss of her beloved spouse, Jody Smith made a point of saying that as horrible as cancer is; it can give you many unexpected gifts. She said that through their cancer journey, they never felt more loved, appreciated, and supported.

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1. Canadian Cancer Statistics 2007, Canadian Cancer Society www.cancer.ca
2. Managing Small Thyroid Cancers, Ernest L. Mazzaferri, MD, JAMA, May 10, 2006
3. Disparities between male and female patients with thyroid cancer: sex difference or gender divide? Andreas Manchens, et. al, Clinical Endocrinology (2006) 65, 500-505

Butterfly

by Sheri Walters
(with permission)

Butterfly, oh butterfly, why do you hide in the shadows?
Spread wide your wings, let your heart sing
And come dance with me in the meadow

Butterfly, oh butterfly, why do you fear?
You'll never stray, I'll lead the way
Just follow the path, I'll be near

Butterfly, oh butterfly, have you no hope?
Drink of the sun, our life's just begun
Thro time's hills and valleys we'll lope

Butterfly, oh butterfly, dare you to dream?
On our hearts we depend, shall we follow the wind
And consign to the fates grander scheme?

Send us your poems.
Email thryvors@sympatico.ca

Dreaming of a Cure

by: Muriel McMahon, Analytical Psychologist

Cancer is a nightmare word. Regardless of the type of cancer, it is a word that comes to most of us with a mountain of emotional baggage attached. Even when it is a 'good cancer', as Thyroid Cancer is oftentimes defined, it is a diagnosis that opens us to our deepest fear, to our most hidden darkness. How not to let this darkness win, is the intention of this article.

I was diagnosed with a cold nodule thyroid irregularity and stumbled through the shadows of a possible cancer diagnosis. It was a frightening and soul sucking 6 months. Yet, on the heels of my post surgery celebration that my nodule was benign, my sister was given a positive diagnosis.
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Oh, such irony in that last statement. My sister's diagnosis was positive with respect to the presence of cancer in her thyroid nodule, but negative with respect to the challenging journey that lay ahead of her.

While I felt like I had dodged a bullet, my sister was struck down. Beyond my own 'survivor guilt', beyond the questions of why one nodule would be clean and the other not, I knew enough about my own fears to try and be a witness and a support for hers. Walking in the dark is scary; sometimes we need someone to hold the light for us when we are stumbling.

Recent breakthroughs in neuroscience and technology have allowed us to witness the plasticity of the brain. On MRI we are able to see how positive imaging, relationship, and in depth psychological interventions can alter the brain and even undo emotional trauma. It is hypothesized that there is a self regulating and self healing mechanism in the body that in some cases can reverse the effects that were once believed to be static and permanent. There appears to be an acausal relationship between dis-ease and disavowed emotional affect. Please do not misinterpret this theory to blame the victim for illness. Rather, see and understand that even in the face of illness, dis-ease, and trauma, the body has the capacity to engage a self-healing response if the fears, anxieties and confusions can be contained and mediated.

One of the best ways I know to contain disavowed affect is the symbol, the imaginative image. The symbol or the imaginative image builds a bridge between the pains of yesterday, the realities of today, and the possibilities for tomorrow. This is not just about the power of positive thinking. This is about finding an image or symbol to hold the potentially destructive energies of unconscious fear, anger, and despair. Through the symbol, these unconscious affects can be made conscious so that the body can constellate its own self healing potential. This is about edging out the fears that lurk in the darkness of a cancer diagnosis with the flickering light of hope, beauty and meaning. C. G. Jung, the imminent Swiss psychologist said that we can endure just about anything if we can find meaning in it. Finding meaning is about making a place for the images and symbols that come to us; even if they come to us through the darkness of a cancer diagnosis.

Where do these healing symbols and images come from? Ah, from the simple genius of the dream. From the ancient wisdom of oracles like the Tarot or I Ching. From the expressive beauty of a dance, a poem, a painting, a symphony, a piece of clay. From the silent comfort of meditation and prayer. Creation is the other side of the coin of destruction. Do not underestimate its power.

I remember going to my ailing sister in the depths of her thyroid treatment despair and throwing the I Ching with her. In that ancient oracle she found a truth she could hold in the darkness. It wasn't what cured her, but it was a beacon in the storm. It reminded her that there was meaning in her life, even a life with cancer. It was a signpost to help her find her way. While the surgeries, medications, diets, radiation, and treatments were part of my sister's story, they were not the whole story. In my sister's cancer story, the caterpillar of cancer entered the darkness and with the guidance of her symbols, eventually emerged from the cocoon of fear to become a butterfly of hope and healing.

As a Jungian analytical psychologist, I have been witness to the incredible healing potential in the symbol. I have been witness to the genius of the dream. I have been witness to the self-regulating mechanisms in the psyche. Again, the purpose of this writing is not to suggest anything but an acausal relationship between unconscious affect and dis-ease. Psyche and soma are two side of the same coin. Heads, some of us win. Tails, some of us lose. Either way, the coin put into the right slot machine, will yield symbolic gold. Of this I am certain. Meaning is found, bridges are built, and the healing of body and soul is assisted through the symbol. So, even in the darkness of a cancer diagnosis and its inherent treatment, let your dreams awaken you, support you, heal you, startle you, create you!

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Ask Thry'vors Q&A

In regards to thyca surgery outcomes, we asked Irving B. Rosen, MD., FRCS (C) FACS, surgeon Mt. Sinai Hospital (and member of Thry'vors Medical Advisory Panel):

1. Patients are often very concerned about how their neck will appear after their initial thyroidectomy surgery. Generally speaking, can the scar be located on the neck to minimize its visibility?

2. Do surgeons monitor the scar healing after surgery? What do they look for?

3. What can patients do to minimize the appearance of the scar?

Dr. Rosen responded:

Referring to thyroidectomy incisions, surgeons are quite aware that the incision is uppermost in patients' minds particularly since the majority of patients are young women.

The incision is usually placed in a normal skin crease and can be 2 to 3 inches long depending on the patient's body build and the size of the thyroid tumour. Usually the incision heals well with difficulty in recognizing scar afterwards depending on the individual. The patient is monitored for good wound healing after. Sutures are removed early on. Sometimes sutures are placed beneath the skin and do not require removal as they dissolve on their own.

Surgeons look at the wounds to detect infection or keloid (overgrowth of the wound) or discoloration. For infection antibiotics are used. To facilitate good wound healing, steroid or Vitamin E ointment may be prescribed.

Where a keloid has become established, steroid injections, laser therapy or silicone patches can be prescribed or surgical resection may be required.

Patients vary in their individual ability in wound healing. Patients should avoid irritating their incisions (fingering their incision, overexposing it to the sun light) and accept the fact that incisions improve with time and that improvement again is an individual matter. Makeup can be applied to the healed incision and it is best to discuss this with the surgeon.

Most patients wind up with an excellent cosmetic effect to the point that it is not noticeable. Some work is being done to perform surgery through an incision away from the neck or through a scope but this is not standard practice.

Don't forget to ask YOUR questions by email (atten: Lynda) **askthryvors@sympatico.ca** or by mail (see back cover for mailing address).

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

Recipe Box

The "Berry" Best of Summer (LID friendly)

"Doubtless God could have made a better berry (than the strawberry), but doubtless God never did".

William Allen Butler

BANANA AND STRAWBERRY "ICECREAM"

1 banana for each person.
1/2 cup of strawberries for each person.
sprinkle of honey or sugar - to taste

Slice fruit, keep 1 whole strawberry per person for garnish. Place sliced fruit on a lightly oiled baking sheet and freeze overnight. Remove from freezer and blend all the ingredients until they have the consistency of icecream. Add sugar or honey to taste. Can re-chill blended fruit if needed -but don't leave for over an hour or it will become like an iceblock. Place in individual serving bowls and garnish with reserved strawberries.

STRAWBERRY LEMONADE

1 cup water
3 fresh strawberries, sliced
1 cup white sugar
1 tablespoon honey

7 cups water
1 3/4 cups fresh lemon juice
2 slices orange

In a saucepan, combine 1 cup water, strawberries, sugar and honey. Bring to a boil, and simmer 10 minutes, stirring occasionally. Cool to room temperature, cover, and chill.

In a large pitcher, mix together water, lemon juice, and orange slices. Stir in cooled syrup; chill. Serve in a tall glass over ice.

New Recipes Added to the Thry'vors LID Recipe Index

Thry'vors LID recipe index now has over 300 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.

Pictures from Microsoft Clipart.

Upcoming Events

Thry'vors:

Annual General Meeting

Date and time: Saturday, June 2, 2007, 9:00 – 12:00
Location: Royal York Hotel, Alberta Room
100 Front Street West, Toronto
Please advise us of your attendance by contacting Rita Banach, President, at thryvors@sympatico.ca or 416-487-8267

Thyroid Foundation of Canada Chapters:

Public Education Meeting - London, Ontario

Topic: What we have learned about Postsurgery Management of patients with Thyroid Cancer'
Speaker: Dr. Irina Rachinsky, Nuclear Medicine, LHSC, South St. Campus
Date and time: May 15, 2007, 7:30 - 9:00 p.m.
Location: LONDON CENTRAL LIBRARY (Galleria), Stevenson & Hunt Room
For more information call: 519-649-5478

Public Education Meetings - London, ON

Topic: 'Parathyroid and Calcium'
Date: September 18, 2007
Time: 7:30 - 9:00 p.m.
Place: LONDON CENTRAL LIBRARY (Galleria), Stevenson & Hunt Room
Speaker: Dr. Terri Paul, Endocrinologist, St. Joseph's Health Centre
For more information call: 519 - 649-5478

Informal Thyroid Discussion - Kingston, ON

Date: Sunday May 27, 2007
Time: 3:00p.m. - 4:00p.m.
Place: Loblaws Upstairs, Kingston Centre
For information call DRUGStore @ 613-530-3414 or Margaret @ 613-545-2327

Strawberry Social - Ottawa Area Chapter

Date: Sunday, June 24, 2007
Time: 10:00 a.m.
Place: Lansdowne Park
Cost: Donations only
For information call: 613-729-9089

Other Events:

Symposium
University of Western Ontario - London, ON

Topic: The Diagnosis and Management of Thyroid Cancer
Date: Saturday, May 26, 2007
Time: 8:00a.m. - 3:00 p.m.
Place: University Hospital - Auditorium A
Register on-line at www.schulich.uwo.ca/medicine/cme
CME office - 519-66-2111 x81370

Thyroid Foundation of Canada and the Endocrine Society

Patients' Forum
Date: Friday June 1st
Time: 6:00 to 9:00 p.m.
Place: Royal York Hotel, Main Ballroom
Speakers include: Norma Beauchamp, Dr. Alice Cheng, Dr. Wendy Rosenthall, Dr. Jack Wall, Dr. Terri Paul and Dr. Ronald Goldenberg.
Agenda available at www.thyroid.ca

Tell us what you think

Your comments and suggestions are welcome.
Editor: Rhonda McMahon
Graphic Design provided by (ursula@litmusdesign.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 Thryvors.org.

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

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