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This is the 5th in a series of seasonal newsletters, from the *Canadian Thyroid Cancer Support Group (Thy'vors) Inc.* Your comments and suggestions are most welcome. Please direct your comments to the Listserv Committee at [thryvors@sympatico.ca](mailto:thryvors@sympatico.ca)

## Thy'vors' AGM in Oakville

On May 1, 2004 the *Canadian Thyroid Cancer Support Group (Thy'vors) Inc.* held its third Annual General Meeting at Wellspring, Oakville, Ontario. It was a wonderful opportunity to take care of some important business items while meeting with some of Thy'vors members – some being with us from when we started as an organization, and some brand new (one just called us for the first time that same morning!). We brought together members from various parts of Southern Ontario and had one member communicate by conference call from Nova Scotia as well.



The AGM was held at Wellspring in Oakville

Annual general meetings are great occasions to look back on the accomplishments of the past year and look towards future aspirations.

Some of the discussions at our meeting included for example: a review of the distribution of our new print materials (a new Thy'vors brochure, and a booklet *A Patients Guide to Thyroid Cancer for those diagnosed with papillary, follicular or hürthle cell cancers*),

a review of our financial position including our grant from the Ontario Trillium Foundation, and various committee reports (fund raising, listserv, website, media, medullary resource working group).

Over the next year we hope to start some new projects, such as: add a glossary to our website resources, research the options to evolve resources for medullary

Thy'vors is both an incorporated not-for-profit group and a registered charitable organization. Our main project is our listserv information and support tool. We also provide an excellent website ([www.thryvors.org](http://www.thryvors.org)), and print materials for thyroid cancer patients as well as providing other means of support.

Donations gratefully accepted and acknowledged with a receipt for tax purposes:

**Canadian Thyroid Cancer Support Group (Thy'vors) Inc.**  
**PO Box 23007**  
**550 Eglinton Avenue West**  
**Toronto, ON**  
**M5N 3A8**

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## AGM in Oakville ...continued

*(Continued from page 1)*

cancer survivors, and to create a protocol for emergency situations (such as for emotionally distraught persons) as they may arise from our listserv or other communications. Another item raised at the meeting was to look at establishing a strategic plan and governance document to help guide the board members of Thry'vors towards building the strength of our organization. One of the other recommendations coming from the meeting was for a "Frequently Asked Questions" about the Low Iodine Diet. This has already been written and appears on our website and in our Listserv files. Please

have a look at this wonderful resource.

Behind the scenes at Thry'vors, the Board of Directors and other committee members work hard each day to help administer the organization. It is not always apparent to the members of the listserv, but a great deal of behind-the-scenes activity goes into making an organization like Thry'vors thrive!

You can view the material from the May Annual General meeting at our website:

Agenda and Committee Reports

[http://www.thryvors.org/pdf/Thryvors\\_AGMagenda\\_04website.pdf](http://www.thryvors.org/pdf/Thryvors_AGMagenda_04website.pdf)

Annual General Meeting  
Minutes May 2004

[http://www.thryvors.org/pdf/Thryvors\\_AGMminutes2004.pdf](http://www.thryvors.org/pdf/Thryvors_AGMminutes2004.pdf)

The directors of Thry'vors are interested in your comments & suggestions, and especially welcome your offers to help grow our organization. Please e-mail us at

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

On behalf of the Board,  
Rita Banach President (Toronto, ON)  
Beth Rajnovich Vice-President (Bedford, NS)  
Grace Wright Secretary-Treasurer (Toronto, ON)  
Dianne Dodd Director (Ottawa, ON)  
Gilda Tarrantino Director (Toronto, ON)  
Lorilea Errat Director (Chesterville, ON)

More doctors  
are listing  
our website  
on their clinic  
websites

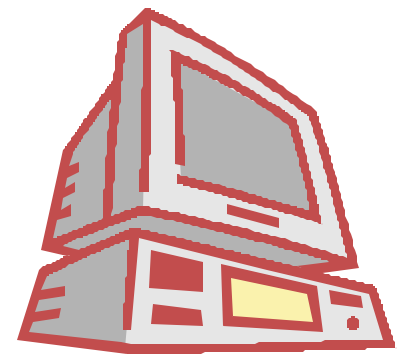
## Thry'vors on the Web

Thry'vors has a growing presence on the internet thanks to the efforts of our website co-ordinator (Beth) and the volunteers arranging the distribution of our patient booklets and brochures to doctors and treatment centres across Canada (Gilda and Rita).

GOOGLE now ranks our listserv homepage at the very top of the search list for "Canadian Thyroid Cancer Support Group". The Thry'vors website [www.thryvor.org] will move up the search engine list as more people access the site and other websites list Thry'vors as a link.

As a result of receiving our brochures and booklets, more doctors are listing our website on their clinic websites (eg B.C. Childrens' and Women's Health Centre) or personal practice sites (Dr. Harper, Hamilton Health Sciences/McMaster).

If you have any suggestions on how we can broaden awareness of Thry'vors please send an e-mail to [thryvors@sympatico.ca](mailto:thryvors@sympatico.ca).



## Listserv Setting Update

As a result of spammers hitting Yahoo Groups (including the Thy'vors listserv) we had to temporarily set the listserv to a "moderated" setting where all messages require approval by moderators before being sent to the listserv members. As a result of improved filters at Yahoo Groups the spam has stopped and we've reset the

listserv back to the unmoderated setting where messages are sent to members as they are posted.

If spam reaches our listserv, please ignore it and DO NOT reply to it. Our listserv moderators will delete the spam message from our archive and report the spammer to their internet

service provider and Yahoo Groups.

If you would like to learn more about how to protect yourself from spammers, at our homepage [<http://www.groups.yahoo.com/group/thryvors>] click HELP in the upper right corner of the screen and search for "spam".

## Low Iodine Diet FAQs

The Canadian Thyroid Cancer Support Group (Thry'vors) Inc. has received many inquiries about the low iodine diet (LID). Patients undergoing radioactive iodine treatment are often asked by their physicians to adhere to a low iodine diet in the weeks before treatment. The actual diet itself, including a list of restricted foods, varies greatly amongst treatments centres across Canada and

this causes confusion and concern for patients.

A new Thy'vors publication titled FREQUENTLY ASKED QUESTIONS ABOUT THE LOW IODINE DIET has been prepared by Julie Lacasse, MSc, RD and Nancy Schwartz Williams, PhD, FDC. This publication has been reviewed and approved by the Thy'vors medical panel. The LID FAQ provides information to help

understand the reasoning behind the diet and to bring clarity to the food preparation and meal planning process. For a specific diet plan you should consult with your doctor.

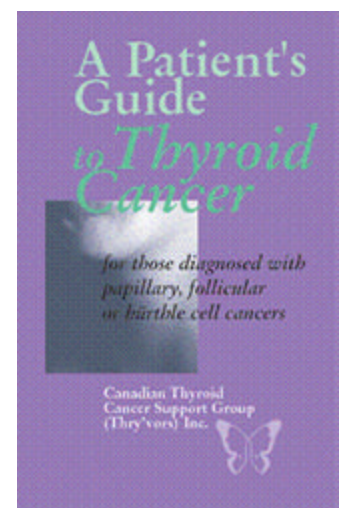
The new LID FAQ publication can be viewed at our website: [http://www.thryvors.org/pdf/Thryvors\\_thyrogen.pdf](http://www.thryvors.org/pdf/Thryvors_thyrogen.pdf)

The new LID FAQ publication can be viewed at our website.

Our booklets and new brochures are being distributed to doctors and treatment centres across Canada.

So far 2,850 brochures and 2,850 booklets have been distributed.

If you would like to take some brochure and booklets to your doctor, please contact Rita at [thryvors@sympatico.ca](mailto:thryvors@sympatico.ca)



## PET/CT Government Policy

There have been many posts on our listserv about the recent policy decisions by the Federal and Ontario Government to deny Canadian patient access to PET/CT scans that are used to detect thyroid cancer tumours that are not evident by radioactive iodine scanning. Several of our members urgently require the PET/CT scanning to detect persistent or recurrent thyroid cancer.

As a registered charity, Thry'vors must keep advocacy activities to less than 10% of our operations

but we work collaboratively with other organizations such as the Canadian Cancer Advocacy Network to make sure the needs of thyroid cancer survivors are understood. Many of our members have sent letters to their members of parliament and members of provincial parliament.

Dr. Driedger reports that there has been no change in government policy. The Ontario Ministry of Health is working toward allowing some limited use of PET. At present, the best doctors can do is to

request that essential PET scans be performed in the USA. Those cases that are approved by the Ministry will be paid for by them.

So, it is important to keep up the pressure and build awareness of this critical patient need with government policy makers.

For the background information on this issue as well as links to web articles & government agencies see message number 7762 in our listserv archive - <http://health.groups.yahoo.com/group/Thryvors/message/7762>

### New Patient Resources on the Web

#### ADDITIONS TO THE THRY'VORS WEBSITE [WWW.THRYVORS.ORG]

Low Iodine Diet Frequently Asked Questions -  
[http://www.thryvors.org/pdf/Thryvors\\_thyrogen.pdf](http://www.thryvors.org/pdf/Thryvors_thyrogen.pdf)

Thry'vors Info Sheet on Thyrogen  
[http://www.thryvors.org/pdf/Thryvors\\_thyrogen.pdf](http://www.thryvors.org/pdf/Thryvors_thyrogen.pdf)

AGM 2004 Minutes  
[http://www.thryvors.org/pdf/Thryvors\\_AGMminutes2004.pdf](http://www.thryvors.org/pdf/Thryvors_AGMminutes2004.pdf)

Glossary of Thyroid Cancer Terms  
[http://www.thryvors.org/pdf/Thryvors\\_glossary.pdf](http://www.thryvors.org/pdf/Thryvors_glossary.pdf)

#### JULY/04 UPDATES TO DR. DRUCKER'S WEBSITE [WWW.MYTHYROID.COM]

Pregnancy & Thyroid Disease  
<http://www.mythyroid.com/pregnancy.htm>

Why did I get Thyroid cancer  
[http://www.mythyroid.com/why\\_did\\_i\\_get\\_thyroid\\_cancer.htm](http://www.mythyroid.com/why_did_i_get_thyroid_cancer.htm)

Thyroid Surgery  
[http://www.mythyroid.com/thyroid\\_surgery.htm](http://www.mythyroid.com/thyroid_surgery.htm)

Radioactive iodine  
<http://www.mythyroid.com/Radioactive%20iodine.htm>

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Several of our members urgently require PET/CT scanning to detect persistent or recurrent thyroid cancer.

## New Patient Resources on the Web...continued

(Continued from page 4)

Post-Treatment Follow-up  
<http://www.mythyroid.com/follow-up.htm>

### NEW ON THE US THYROID CANCER SURVIVORS' ASSOCIATION WEBSITE

7th Annual Conference October 22-24, 2004 – Chicago  
<http://www.thyca.org/conferences.htm>

Know Your Pills (educational NOT medical advice)  
<http://www.thyca.org/knowpills.htm>

How to Take Your Pills (educational, NOT medical advice)  
<http://thyca.org/levothyroxine.htm>

### NEW ON THE AMERICAN THYROID ASSOCIATION CONFERENCE WEBSITE

Video transcript of 75th Annual Meeting September 2003  
<http://www.blueskybroadcast.com/Client/P1/indexa.html>

Thyroidology on the Internet: The Good, The Bad, and The Ugly moderated by: Paul W. Ladenson, M.D.

What's Out There in Thyroid Cyberspace? An Overview of Thyroid-Related Websites presented by: Paul W. Ladenson, M.D.

What Thyroid Patients Seek and Find on the Internet presented by: Matthew I. Kim, M.D.

Internet Resources for Thyroid Research in the Clinic and Lab presented by: Matthew D. Ringel, M.D.

PET/CT studies  
are not funded if  
performed in  
Ontario

## New LID Recipes

Our index contains over 100 recipes. The recipes below have been added to our index at the listserv homepage:

<http://www.groups.yahoo.com/group/thryvors/files>  
 [in the LID FAQ & RECIPES – 2nd folder]

**Breads, Tortillas and Sandwiches:** Mushroom-Barley Burgers with Sage

**Cereals and Muffins:** Apple-Cinnamon Compote with Toasted Oats, Dry-Roast Granola

**Dips, Salsa, Dressing & Marinades: Fruit Ketchups;** Balsamic Tomato

Salad Dressing; Papaya Salasa; California Marinade, Citrus Marinade; Mediterranean Herb Rub

**Vegetables/Salads:** Asparagus-Orange Salad; Indonesian Salad

**Poultry:** Roasted Chicken with Apples and Onions; Gingered Chicken Breast

**Meat:** Burgers with Roasted Garlic and Rosemary; Peanut-Orange Pork Tenderloin

**Desserts:** banana-strawberry ice-cream; banana-mango ice-cream; strawberry slush; no bake chocolate oatmeal cookies; maple crunch cookies; peanut butter cookies

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

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

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*Offering information  
and support*

## Help Needed

Thry'vors needs new volunteers in every aspect of our organization – but our most urgent needs are for volunteers in the areas below.

### **Finance Committee**

-person(s) with a strong background in accounting (preferably a CA or CGA) who can work with our Treasurer to prepare the 2004 financial statement. (5-10 hours once a year).

### **Board Advisory**

-person(s) willing to give their input into the leadership of Thry'vors by receiving the Board of Directors Weekly Update (once per week by e-mail), commenting on items in the update as requested and as they arise. This responsibility includes the option of joining the board of directors at the next AGM (May 2005) (1/2 hr once per week, year round).

- person(s) willing to work with the board to complete our governance document (document has currently completed the outline stage). (5 hrs spread out over a few weeks)

### **Fundraising**

-person(s) willing to assist the fund raising chair in producing and distributing fund raising proposals to charitable foundations and corporations. (2 hours per month, year round)

### **Annual General Meeting 2005 Planning Committee**

-person(s) to assist in the planning and implementing of our May 2005 AGM in Ottawa

### **Medullary Resource Working Group**

-person(s) to help evolve medullary patient resources

### **Media Committee**

- person(s) help prepare and distribute material to the media as part of Thyroid Month, June 2005

- person(s) share your thyroid cancer story with local media (4-7

hours May-June 05)

- person(s) to help introduce Thry'vors to local reporters (one-time suggestions)

### **Listserv Committee**

- person(s) to help manage, develop and promote the listserv (shared responsibility with other committee members, hours can be flexible)

- person(s) to help develop and distribute the quarterly newsletter (3-6 hours, quarterly)

