

IN THIS ISSUE:

- 1. Have Your Say
- 2. Listserv Update
- 3. One Year Anniversary
Thry'vors Website
- 4. Report Submitted to Ontario
Trillium Foundation

- 5. Mid year check-in
- 6. Call for volunteers
- 7. New Thyroid Cancer
Resources on the Web
- 8. New LID Recipes

- 9. CT/PET government policy
- 10. Helpful Hint

Volume 3, Issue 3
Fall 2004

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

Thry'vors News



This is the 6th 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 Listserv Committee at thryvors@sympatico.ca

Have Your Say

The organizing committee, Louise Beggs (Chair), Dianne Dodd, Lorilea Errat and June Rose-Beaty (TFC Ottawa), for next years' Annual General Meeting and mini-conference, to be held in Ottawa, May 13, 14, 2005, would like to get feedback on the draft program.

This meeting will include the first ever, Wally Patching Memorial Lecture, and we are excited to have Dr. Irving Rosen as our guest. He will speak on "Thyroid Cancer Recurrence". As well, we will have a dinner and social evening Friday May 13, the Thry'vors Business and Annual General Meeting, and a panel discussion on Thyroid Health, which

will be co-sponsored by the Thyroid Foundation, Ottawa Chapter. We will be booking a block of rooms at a local hotel. More details will follow as we work out the program. The meeting will coincide with the Ottawa International Tulip Festival, so why not plan a mini-holiday around it? We hope everyone will plan to come to Ottawa for this meeting and conference, to learn more about managing all aspects of thyroid cancer.

As we have some time in our day's schedule for one or two sessions on the social/psychological aspects of thyroid cancer, we would like your input as to what you would like to see. Below are a few examples of ideas for sessions. Let us know what you think.

- experience sharing -- exchanging survival

- stories
 - art therapy
 - meditation
 - caregivers session
- emotional aspects of thyroid cancer

We are also looking for a patient voice to add to our panel of experts on thyroid health. If anyone would like to volunteer to speak for 5-10 minutes on their experience of thyroid cancer, please let us know. You don't have to be an expert, but just tell your story. It is important to have a patient voice.

Please email: Dianne.Dodd@pc.gc.ca with comments.



May 2005 Mini –conference corresponds with Ottawa's International Tulip Festival

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

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

Listserv Update

Yahoo Groups, our free listserv host provider, is exploring ways to develop new revenues. Advertisements have been added to e-mails and to our homepage. These ads are clearly marked "Yahoo Sponsored" and are not from Thry'vors. In order to limit confusion, we will be moving all of our patient resources, except the LID recipe index and member-mini-bios, to the

Thry'vors website:
www.thryvors.org.

Over the next few months, Yahoo Groups will be developing new fee-for-service packages that provide the option to limit ads.

While some listserv services will continue to be provided for free, the services will have very limited archive capacity and limits on the number of e-mails

that can be exchanged per month.

The listserv committee and Thry'vors board will need to review these options to evolve our Thry'vors listserv in order to make sure that it continues to be a useful and accessible resource for Canadian thyroid cancer survivors and their families.

One Year Anniversary of Thry'vors' Website

As "webmistress" I am happy to announce that our website (www.thryvors.org) has been up and running for over a year. The site was launched on September 28, 2003, (in the midst of Hurricane Jaun!) and has been running smoothly since. The content on the site has grown considerably since this time. Copies of all of Thry'vors' publications are available on the site in PDF format for viewing and printing, as is a list of links to information on thyroid cancer, and a section on news and events, among other resources.

Recently, work has been done to promote the site. The results have been promising as our site moves up the results lists on the major search engines. Work will continue in this area so that more people with thyroid cancer are able to find us online easily.

We would like the website to be an ever-evolving resource; a site that you will visit again and again as a way to stay connected with what Thry'vors is doing. If there is information you would like to see on the site, or you have other suggestions, please let

me know by writing to:
beth.rajnovich@ns.sympatico.ca

*Beth Rajnovich,
Webmistress,
www.thryvors.org*



www.thryvors.org

Our website
has been up
and running for
over a year

Trillium Project Completed

In September 2003, the Canadian Thyroid Cancer Support Group (Thry'vors) Inc. was granted \$14,000 by the Ontario Trillium Foundation, to be utilized within one year.

The main purposes of the grant were to reach out and support individuals suffering from Thyroid Cancer, including: developing and disseminating print materials, establishing a website, supporting the listserv development and providing in-person meetings where numbers warranted.

Specifically, we agreed to design, print and distribute 2,000 brochures and 1,300 booklets. As well, a condition of our grant was that we form a medical advisory panel who would vet our written material and who could be available for medical questions arising from the listserv or elsewhere.

I am happy to report that our Trillium project was overwhelmingly successful. Early on we established a medical panel of 6 doctors who are experts in the field of thyroid cancer. Several of them are

renowned researchers; one is a top expert in the area of nuclear medicine; one is a surgeon and one a psychiatrist. They played an active and important role in editing our printed matter, especially our booklet "*A Patient's Guide to Thyroid Cancer - for Those Diagnosed with Papillary, Follicular or Hurthle Cell Cancers*".

We surpassed our distribution goals, and to date we have sent out 3,408 brochures and 3,437 booklets. We have collected positive comments from the doctors who are helping to distribute the material as well as from patient-recipients. (Initially, we sent out invitations to distribute our brochure and booklets to 340 doctors and cancer clinics, who then requested more copies). We now have an attractive, strong and important website - filled with useful information. Our listserv is vibrant, lively and a large source of information, comfort and support.

We look forward to continuing all of the

initiatives started in the last year. Most of our medical panel members have agreed to continue with us. We are pleased to announce that we have added a pharmacist to our roster. Our listserv membership grows daily. Our website is frequently updated. Our booklet and brochures are still being requested and distributed. And, we are looking towards holding more in person meetings in the future. All in all, a successful project!

Special thanks to Patricia Sharkey, our listserv coordinator; Beth Rajnovich, our webmistress; Gilda Tarantino, our distribution coordinator, and Dianne Dodd and Diane Patching, who have both served as the Medical Advisory Panel liaisons. Thanks also goes out to all of those members who replied to our request for your thoughts on why Thry'vors is needed – not only did we enjoy reading your responses but they were a valuable addition to our report.

To date we have sent out 3,408 brochures and 3,437 booklets

Mid Year Check-in

Each year at the Annual General Meeting in May, the Board of Director sets out an ambitious plan for the next year and volunteers set off to achieve these goals. As we are half way through the year, it is a great time to check in and see what has been accomplished so far and what Thry'vors plans to do next.

The following tasks from the May 2004 AGM (to name a few) have been accomplished:

- A glossary of thyroid cancer terms has been developed and is available on the

website and in print.

- A FAQ (frequently asked questions) document on the Low Iodine Diet (LID) has been developed and is available on the website and in print.
- New volunteers have joined the Listserv committee (but more are needed!).
- The Media Committee is up and running once again under the guidance of Diane Patching.
- Thry'vors has been successfully working to reconfirm the participation of members of our Medical Advisory Committee.
- Plans are underway for the 2005 AGM and

Mini-Conference in Ottawa.

Over the next few months Thry'vors plans to:

- Fundraise to cover ongoing operation expenses and possible new expenses such as service fee for operating the listserv
- Work on a strategic plan for the organization.
- Promote the website and add new resources.
- Develop new resources to support thyroid cancer patients.
- Finalize plans for the May 2005 AGM/Mini-Conference
- AND MUCH MORE....

Check in and see what Thry'vors has accomplished so far

LISTSERV HELPFUL HINT

Yahoo Groups receives their revenue from ads. In order to stop ads from coming into your e-mail account, make sure that your Group account marketing preferences show you do not want to receive ads.

How to check your group account status:

1. Sign in at the Thry'vors listserv homepage with your ID and Password: <http://www.groups.yahoo.com/group/thryvors>
2. At the top of the screen click "MY ACCOUNT"
3. Run down the list of marketing methods and make sure each one says "NO".
4. Click SAVE CHANGES at the bottom of the screen

Call for Volunteers

It is one of the most beautiful compensations of life, that no man can sincerely try to help another without helping himself.

~ Ralph Waldo Emerson

Volunteers are the heart of charitable organizations, and Thry'vors is no different. Thry'vors began because a group of people with thyroid cancer came together with a shared vision – that others with the disease would have access to information and support in ways that they had not. Since that time other volunteers have pitched in – people who have found support and information through Thry'vors and wanted to lend a helping hand. To them we say thanks!

Volunteers are the heart of charitable organizations.



In order to continue to offer services and take on new projects, we are always looking for new volunteers to help out. Volunteers can help in many ways such as joining a committee or helping with a special project or event. Volunteers can contribute a few hours a week or a couple hours a month. There are currently two initiatives where help is needed:

1. The Media Committee is working to produce materials for next year's thyroid month, June 2005. New members are welcome on the committee. The committee chair, Diane Patching, hopes to have representatives in all areas of the country who would be willing to talk to their local media whenever necessary. The Committee plans to

discuss and prepare a submission over the winter so please feel free to join with suggestions. Please contact Diane at dpatching@sympatico.ca and join our media committee.

2. The Listserv committee is also looking for volunteers. Changes to Yahoo Groups may result in the reduction of our listserv archive storage space. Therefore the committee needs volunteers to help review the archive in order to save messages that reflect our group's history and specific patient experiences. If you are interested in helping out with this important project please contact us at thryvors@sympatico.ca

If you are interested in finding out about other volunteer opportunities write to us at: thryvors@sympatico.ca

New Thyroid Cancer Resources on the Web

There is a new listserv of the US Thyroid Cancer Survivors' Association named The Thyroid Cancer Mental Challenges Support Group

<http://groups.yahoo.com/group/thycamentalchallenges/join>

This is a private e-mail group, addressing the emotional issues that some thyroid cancer survivors deal with. These may or may not be related to our thyroid cancer or its treatment. However, they still affect our lives.

Examples include:

- Day to day coping with life as a cancer survivor: learning to rely on hormone replacement instead of our body's own thyroid hormone, adapting to periodic testing, & other life disruptions.
- Mental health issues that may accompany a cancer diagnosis; e.g.: depression, fears, panic attacks, & how they affect our lives.
- Brain fog: inability to think quickly to solve problems, memory loss, & dealing with fatigue that affects our concentration or mood.

- Returning to work or school: coping with challenges of competition, meeting deadlines, continuing to perform.

This group offers a supportive setting in which to share our experiences and solutions. "We aim to lessen feelings of isolation. We help each other build on our strengths and learn how to cope with our life changes since our diagnosis. We give encouragement and offer compassionate support. This group is not a therapy group or a form of professional treatment. We ask participants to seek help from their doctors for their individual medical and mental health needs." This group is open to anyone who wishes to join. After you join the group, you'll be able to read all the

posts from the other group participants. You may send a message if you choose to do so. The group moderators review all messages. This group is dedicated exclusively to supporting members who experience emotional and mental health issues that accompany living with Thyroid Cancer. Posters who have questions or comments about other aspects of thyroid cancer will be directed to an appropriate listserv (e-mail support group). (See www.thyca.org for all ThyCa support listservs). By posting to this email support group, the poster understands and agrees that each email will be reviewed for content and any email may or may not be allowed to be posted in the sole discretion of the moderators.



NEW LID RECIPES

Our index contains over 120 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]

Maple Bake Chicken,
Spiced Chicken,
Country Ribs,
Easy Tomato Salad,
Quick Pickled Beets,
Raspberry Apricot Vinaigrette,
Garlic Dip (Skordalia),
Quebec Carrot Chutney,
Rye Crackers,
Rick's Muffins & Variations (banana, lemon-
poppy seed, berry, nut, fruit),
Almond Macaroons,
Apple Coffee Cake,
Chocolate Pudding,
Almost Sinful Brownies.

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



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



*Offering information
and support*

CT/PET Government Policy

There have been many posts on our listserv about the recent policy decisions by the Federal and Ontario Governments 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.

Ontario patients are being referred to the US for scanning and but face long delays for cost-approval due to the backlog of requests.

Overall, there has been no progress toward a resolution. There needs to be a strategy to bring money to the table

and achieve funding in the various provinces.

Britain has accepted that PET is a cost-effective tool for oncology and some other applications. They are now developing plans to deploy a nationwide network of PET centres.

A Framework for the Development of Positron Emission Tomography (PET) Services in England

http://www.dh.gov.uk/Consultations/LiveConsultations/LiveConsultations/Article/fs/en?CONTENT_ID=4086525&chk=MNa2IG

Canada is the last developed country in the world not to have a plan for PET services .

