

# Clearing up the Confusion and Improving Patient “Compliance”:

## The TCC-Thry’vors Low Iodine Diet

*Reasons to Hope, Knowledge to Cope:  
Innovations in Cancer Patient Education*  
May 31 - June 2, 2007 Montreal

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Grace Wright  
Thyroid Cancer Canada

*SLIDE #1*

*Good afternoon and thank you for being here. It is very encouraging to see such a strong turn-out for a session exploring “Volunteerism in Cancer Care”. I am here representing Thyroid Cancer Canada, or “Thry’vors”, a grassroots organization made up entirely of volunteers who are all thyroid cancer survivors. Today, I will be speaking about who we are, what we do, and, as an example of the positive and important impact that volunteers can have in delivery of quality cancer care, I will be sharing with you the story of the project to develop and launch the TCC-Thry’vors Low Iodine Diet.*



## Volunteerism in Cancer Care: TCC – a Volunteer-led Patient Group

Thyroid Cancer Canada is a national organization of thyroid cancer survivors dedicated to providing emotional support and information to those affected by the disease.

2000: group of Canadians met on a U.S. support website

2002: incorporation and launch of the listserv

2003: obtained status as a registered Canadian charity

TCC is now a primary point of reference for information and support.

## SLIDE #2

*TCC is a national organization of thyroid cancer survivors dedicated to providing emotional support and information to those affected by the disease. The individuals we help include patients at all stages of diagnosis, treatment and follow-up, as well as their family members, loved ones, colleagues and anyone interested in learning more about thyroid cancer.*

*In 2000, a group of Canadian thyroid cancer survivors met on-line through the listserv of the American Thyroid Cancer Survivors Association (ThyCa) and began their own informal support group. By 2002, the group had become incorporated as the Canadian Thyroid Cancer Support Group (Thry'vors) Inc., and in 2003, Thry'vors applied for and was granted status as a registered charitable organization. This status allowed us to begin issuing official donation receipts for tax purposes and to apply for funding from a large pool of prospective donors who provide financial support only to registered charities. Right away, we applied to the Ontario Trillium Foundation who granted us the funds to develop and produce the first edition of our Patient Handbook.*

*TCC has established itself as a primary point of reference for information and support as individuals begin what is often a lifelong and life-altering experience of being diagnosed with thyroid cancer. It's a big job because the number of Canadians coping with thyroid cancer diagnosis, treatment and follow up is increasing every year as reported the 2006 release of Canadian Cancer Statistics.*



# TCC

## How We Help

- member listserv (Yahoo! Groups)
- telephone support
- [www.thryvors.org](http://www.thryvors.org)
  - thyroid cancer information resource list
  - glossary of thyroid cancer terms
  - supportive and informative publications
    - “A Patient’s Guide to Thyroid Cancer” booklet
    - “Thry’vors News” newsletter
    - “TCC-Thry’vors Low Iodine Diet” pamphlet
- patient advocacy

### **SLIDE #3**

*There are several channels through which we provide help.*

***The Member Listserv.*** *As of yesterday, Yahoo reported 697 members registered on the listserv. As we state, “The purpose of the listserv is to provide support for Canadian Thyroid cancer survivors, their families and friends. The listserv is also a communication network to link members with patient education information on thyroid cancer diagnosis, treatment and ongoing monitoring, and living well.”*

***Telephone Support.*** *Recognizing that not everyone has access to or is comfortable with using the internet, TCC volunteers also provide support and information over the phone. This one-on-one service requires a enormous commitment of time and energy on the part of our volunteers, however it remains an important way provide support and the demand for it continues to rise.*

***The Website.*** Visitors to the website will find PDF files of an extensive of materials listed on a thyroid cancer information resource list. These include: (1) a Thyrogen information sheet – thyrogen being a therapy that patients can opt for when having to withdraw from their thyroid replacement medication; (2) a glossary of thyroid cancer terms; and (3) our three publications, “A Patient’s Guide to Thyroid Cancer” in booklet form, the “Thry’vors News” newsletter, and the “Thry’vors Low Iodine Diet” pamphlet. We have also posted member stories and bios, information and links about current events and media articles on thyroid cancer and TCC.

As we say in our Vision Statement, we draw on the medical community to provide a consistently high standard of support in the delivery of our support and information resources to all individuals dealing with the disease. We currently have a 9-member medical advisory panel representing the fields of surgery, psycho-social oncology, endocrinology, nuclear medicine and pharmacology.

***Advocacy.*** In our goals we define advocacy as being the activities involved in expressing the needs of thyroid cancer patients to those who evolve healthcare policy and services – to date this has been largely limited to advocating for provincial and private insurance subsidization of Thyrogen, a drug therapy that helps patients avoid the effects of hypothyroidism when having to undergo radioactive iodine treatment or scanning, by allowing them to not have to stop taking their prescribed thyroid replacement medication. This really boils down to advocating for equal access – to removing the cost of treatment from the factors involved in weighing treatment options.

# The Need for Information and Support

- Most common issues addressed on the listserv include:
  - Low Iodine Diet
  - Scar care
  - Recurrence
  - Fatigue
  - Weight Gain
  - Depression (feeling depressed and clinical depression)
  - Monitoring, scanning & follow up
  - Thyrogen®



## **SLIDE #4**

*To provide you with an idea of the issues discussed on the listserv, this slide lists the most common issues (in no particular order): the Low Iodine Diet, scar care, recurrence, fatigue, weight gain, depression (feeling depressed and clinical depression), monitoring, scanning & follow up, and very specifically, Thyrogen®.*

## Patients Asking Patients

- 20,937 messages have been posted since 2002
- approximately 3,600 of postings (17%) mention "LID" or "iodine"
- postings include questions/comments about:
  - the role of the LID in the success of RAI treatment
  - anxiety about knowing what is allowed and what is not
  - fear of not being able to live without salt
  - inconsistencies in the LID among hospitals and nuclear medicine clinics, which version of the LID to follow



## **SLIDE #5**

*Looking more closely at the statistics of the Listserv activity, 20,937 messages have been posted since its launch in 2002. Of these, approximately 3,600 postings mention the acronym “LID” or the word “iodine”, and “confused” appears in 788 messages, almost as frequently as “scared” which shows up 834 times. The highest frequency is attached to the word “thyrogen” which appears in 3,813 of the postings. In answer to this trend, TCC has posted information about Thyrogen® on its website. The fact that 17% of messages voiced some degree of confusion about the Low Iodine Diet was part of the incentive to take on our most recent initiative, since it was no longer enough that we had created and posted a document called “Frequently Asked Questions about the Low Iodine Diet”.*

*The Low Iodine Diet (widely referred to by its acronym LID) is a strict diet that must be followed by patients preparing for radioactive iodine (RAI) treatment or scan. The thyroid cells are regarded as the only cells in the body that use and absorb iodine. This means that it is possible to target thyroid cells, whether to destroy them or to highlight them on a nuclear image, using a specific radioactive isotope of iodine administered orally to the patient. In order to ensure that the thyroid absorbs as much of the radioactive iodine as possible, it is believed that the body must first be starved of iodine.*

*Increasingly over the last couple of years, patients and concerned caregivers were turning to TCC to answer their questions about the LID, such as*

*“What role does the LID play in the success of RAI treatment?”*

*“What can I eat on the LID?” “What am I not allowed to eat while on the LID?”*

*“How can I possibly live without salt, even for just a few weeks?”*

*“Why do different hospitals in the same city, let alone across Canada, have different versions of the LID?”*

## Volunteers Took the Initiative: The TCC-Thry'vors Low Iodine Diet Project

- Expanding on the 2003 "Frequently asked Questions about a Low Iodine Diet", TCC set out to define a national standard for the Low Iodine Diet
- 19 revisions, reviewed by 36 experts, resulted in the November 2006 launch of the "TCC-Thry'vors Low Iodine Diet"



## **SLIDE #6**

*In 2003, TCC issued a document called “Frequently Asked Questions about a Low Iodine Diet” to provide members with a quick reference in a single source, since a great many of the postings about the LID addressed similar questions. However, one of the more distressing issues around the LID was the lack of consistency in guidelines being provided to patients across the country. Clearly, something beyond the FAQ document was required. So, in 2004, TCC set out to define a national standard for the LID.*

*From the beginning, it was vital that the process be transparent and that reputable experts be involved at every stage. (A document entitled the “Low Iodine Diet Project 2006 – Purpose, References, Writers and Reviewers” tracing the project from inception to end, is available on the website.)*

*In the process of compiling versions of the diet from across the country and critically reviewing as much as had been published as we could dig up, the goal was to get to the root source of the information, including for example unearthing the “mystery of low iodine cows on the East Coast”... The literature showed that dairy products are one of the higher sources of iodine in the Canadian diet.*

*However, a reviewer from the East Coast said that high levels of iodine in milk is a myth, and referred to the low iodine levels in milk on the East Coast. These numbers were in fact lower than were documented for milk from cows elsewhere in Canada. This was a puzzle that we had to solve. After consulting with agriculture experts at the University of Guelph, we were informed of how the levels of iodine in milk can vary regionally, seasonally and with the processing methods used. It was decided, based on the unpredictability of these variations, that in order to be safe, following our motto of “**if in doubt, leave it out**” all dairy products remain completely among the foods to be avoided.*

*The research, consultations, writing, re-rewriting and design, a process spanning from 2005 to 2006, included a total of 19 revisions reviewed by 36 experts, and finally culminated in the November 2006 launch of the “TCC-Thry’vors Low Iodine Diet”.*

# Recruiting the Experts for a Knowledge-in-Practice Approach

Reviewers were recruited, Canada-wide, from the following areas of healthcare, government & food industry:

|  |   |
|--|---|
| Endocrinology, Internal Medicine and Endo. Surgery (8) | Nuclear Medicine & Radiation Oncology (4) |
| Oncology Patient Support & Information (3)             | Pharmacology (1)                          |
| Nursing (2)  | Psychiatry & Psychosocial Oncology (1)    |
| Diet and Nutrition Education (5)                       | Packaging Industry (1)                    |
| Canadian Food Inspection Agency (1)                    | Thyroid Cancer Patients (10)              |

## **SLIDE #7**

*The credibility of our version of the LID lies largely in the care taken to recruit the “right” experts. Reviewers were recruited, Canada-wide, from the various areas of healthcare, government and food industry. To employ a knowledge-in-practice approach we sought input from those currently practicing in the related areas. It is very important for us to acknowledge all the reviewers who volunteered their time and expertise to this project, and we have published their names and affiliations in the “Low Iodine Diet Project 2006” document available on our website.*

*We believed that it was equally important to identify and include patients as key experts, not just end users. Some very important input came from our patient reviewers including the colour coding of green and red, wording that needed to be simplified or clarified, the need to clearly state the importance of the diet and how the treatment works, and to prominently indicate the number of servings allowed in the three relevant categories.*

# When “Compliance” is not a Dirty Word

- Patient-centred care discourages the use language of that suggests or reinforces a power disparity in the patient-healthcare provider relationship
- When it is necessary to follow a protocol, “compliance” can be empowering when patients:
  - understand how it works and why it is important
  - are given the tools to make ‘complying’ easier
  - feel supported while ‘complying’ with the protocol
  - know that others have found the protocol challenging
  - can take an active part in their treatment



## **SLIDE #8**

*Patient-centred care discourages the use of language that suggests or reinforces a power disparity in the patient-healthcare provider relationship and in fact, the word “compliance” is often considered a dirty or taboo word in the patient-centred care environment. So, it may seem odd that a patient group would use the word “compliance” in any of its initiatives. However, based on patients reviews of the TCC-Thy’vors LID, we believe to have touched upon a context in which “compliance” may actually be empowering for a patient.*

*The patient reviews were full of comments articulating their need to feel like the guess-work had been taken out of the low iodine diet. We received comments like: “it clearly explains why we need to do the diet and how the treatment works.” “First time LID’ers are worried and confused enough...with this, a quick glance and we are on our merry hypo way”*

*“This would be a great asset for following the diet. I would suggest it also be sent to hospitals as many do not follow LID. I had to bring in my own food.”*

*“When hypo it would be very handy to have that info posted”*

*“if one doesn’t adhere to it, it may not work or deliver the desired results”*

*“It’s high time there was one LID for everyone. It avoids confusion.”*

*Together with other feedback, we believe the when it is necessary to follow a protocol, “compliance” can be empowering for patients when:*

- the patient understands how a protocol works and why it is important*
- the patient is given the tools to make ‘complying’ easier*
- the patient feels supported while ‘complying’ with the protocol*
- the patient knows that others have found the protocol challenging*
- the patient can take an active part in the treatment prescribed*

# Measuring the Reach of the TCC-Thry'vors LID



- it is being referenced on internet Q&A pages and blogs all around the world
- a story about the TCC LID was featured in the inaugural issue of Wellspring's CANCER SMART newsletter
- careful tracking of the distribution of professionally printed copies of the TCC LID

## **SLIDE #9**

*We are using patient and clinician feedback as well as various measures of the diffusion of the TCC LID to determine its reach and adoption. We have been tracking internet references to our materials and over the past few months, we have been getting some very exciting feedback about the reach of our LID over the internet.*

*For example, references to the TCC LID have been found on blogs based in Australia and Croatia. Also, three weeks ago, in early May, we started getting emails from South Asian addresses asking for the HTML version of the booklet and the diet to be put back on the website. Not everyone can download a PDF file and so it is best to make an HTML version on one's website. What we hadn't know was that our webmaster, who is based in Dartmouth, Nova Scotia, was in the process of uploading the new HTML versions of the booklet and LID. In the 10 days during which the HTML versions were not available on our website, we received 14 email requests for the HTML versions, the first coming the day after the old HTML version had been removed from the website.*

*This curious situation inspired one very research-oriented volunteer to investigate the diffusion of the our LID in South Asia, and she was able to confirm that our LID resources and patient booklet have been referenced by the cancer centres in Bangalore, India and in Ipoh, Malaysia (both regions, interestingly, with high thyroid cancer incidences) .*

*A cancer support network here at home has been instrumental in increasing the awareness and reach of our LID. In the inaugural issue of Wellspring's CANCERSMART newsletter, TCC was invited to submit an article about its LID and how it is helping patients prepare for RAI treatment or scan.*

*We are also keeping careful track of the distribution of hard copies of our publications as the following two slides will illustrate.*

# Distribution of TCC Materials

|   | Brochure     | Booklet       | LID<br>Pamphlet |
|---|--------------|---------------|-----------------|
| Single Sample Copies to MD/HCPs                   | 739          | 739           | 692             |
| Single Copies directly to patients and/or members | 92           | 114           | 69              |
| Bulk orders to MD/HCP                             | 7,590        | 9,005         | 2,275           |
| Copies distributed at events                      | 319          | 224           | 120             |
| Bulk orders by members and/or patients            | 1,209        | 1,200         | 186             |
| Totals  | <u>9,949</u> | <u>11,282</u> | <u>3,342</u>    |

*Brochure & Booklet since March 2004; LID since November 2006*

## **SLIDES #10**

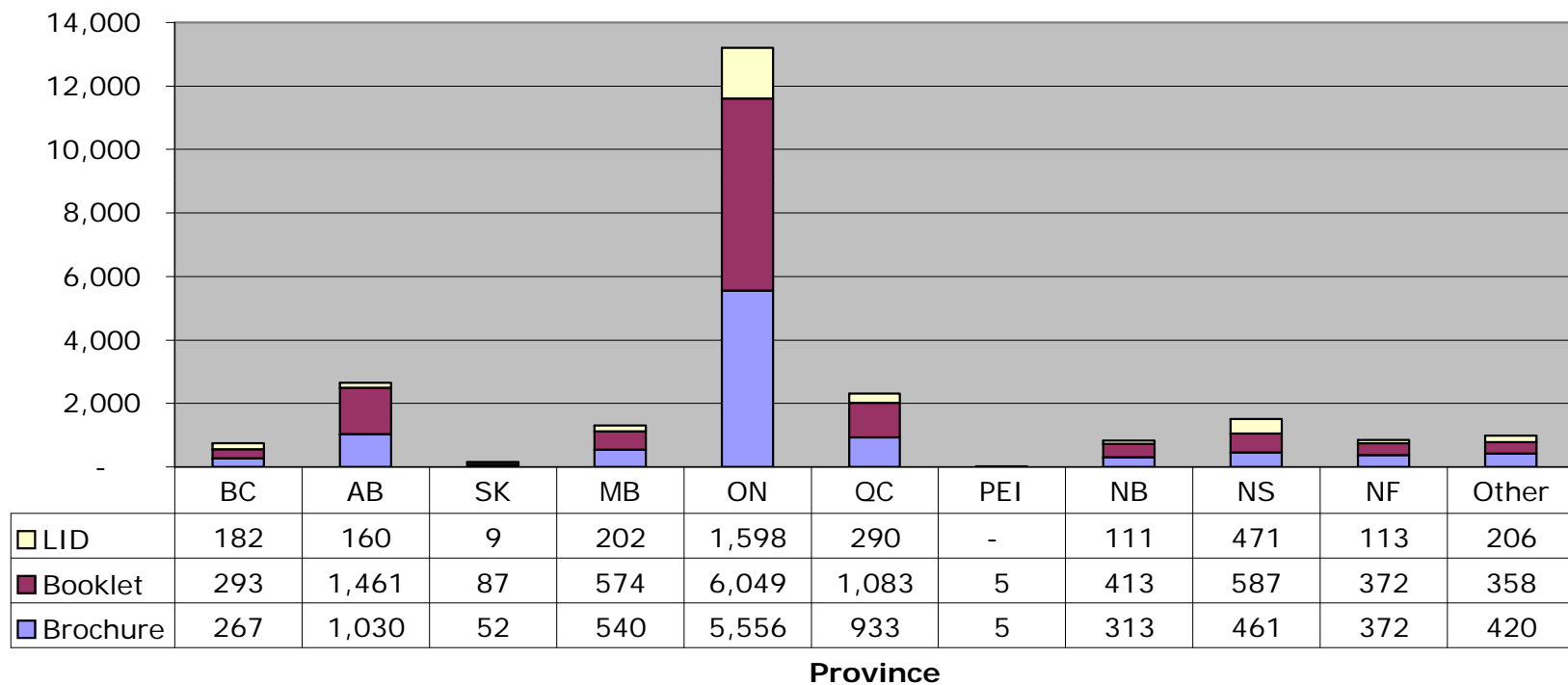
*In November, single sample copies were sent with an explanatory cover letter to clinicians in hospitals and medical centres across Canada, as well as to carefully identified private practitioners. A survey, inviting their feedback, was also included. Comments that we have received to date include: “practical and informative”, “simplicity is great – not an overwhelming amount of information”, “I believe patients will find the LID easier to follow and understand as a result”. Naturally, we have also received suggestions to: emphasize the avoidance of “all restaurant and take-out food”, “add rhubarb juice” [nb. Despite the fact that rhubarb is already listed under fruits to avoid], emphatically state that consumption of iodine will make the scan or treatment ineffective, place more emphasis on the need to partner with one’s physician in following the diet.*

*Largely in response to the sample copy mailing, we have begun receive bulk order from clinicians. Looking more closely at the bulk ordering of 2,275 copies of the LID pamphlet (see the chart on slide #10) 17 hospitals, medical centres or private practices have placed a total of 18 bulk orders of the TCC LID; while most were in Canada, 2 bulk orders were requested from centres in Charleston, South Carolina that came about by a staff member from the Rutledge Tower Endocrine Clinic conducting an internet search for a useful patient resource.*

*We have also received requests from physicians in the Greater Toronto Area for support resources for the Toronto Chinese and Filipino communities. The challenges of access to quality healthcare and information faced by Limited English Proficiency patients is significant and with more resources we do want to take on projects that would make our services accessible to a wider community of individuals seeking information and support.*

# Distribution of TCC Materials

## Distribution by Province



*Brochure & Booklet since March 2004; LID since November 2006*

**SLIDE #11**

*As the chart illustrates, we are sending out more patient guide booklets than brochures. It was also very interesting to note that the provincial distribution of our materials is very similar to the provincial pattern of incidence of new cases of thyroid cancer as released by the statistics released this year by the Canadian Cancer Society.*

# Why Take Volunteer-led Patient Groups Seriously?

We are personally committed

We have lived it and continue to live it

We want to know more ourselves

We want to make it easier for others going through it now



## **SLIDE #12**

*Returning now to the topic of Volunteerism in Cancer Care. One of the challenges faced by a patient-led volunteer group is being taken seriously by the healthcare community and patients alike. We believe that volunteer-led patient groups should be taken seriously because we are personally committed to the cause, we have lived the experience and continue to live it, we want to know more about the relevant issues ourselves, and finally, we want to make it easier for others going through the experience now*

# Challenges Facing Volunteer-led Patient Groups

- Limited time
- Limited funding and resources
- Lack of credibility
- Getting on the radar



### **SLIDE #13**

*Further, there are some other challenges that we face as a group of volunteers. We have jobs and families and other obligations, so our time is very limited. We are working with very limited resources and funds – there are no membership fees and our publications are distributed free of charge. At the outset, there is a lack of credibility about our work, for we are often perceived as ‘just’ patients, or ‘just’ volunteers. Finally, we must work to create awareness about our group and our work – we have to ‘get on the radar’.*

# Overcoming the Challenges

- Making the Most of Limited Time
  - Effective and respectful management of volunteer time, energy, effort and intent
  - Regular and relevant volunteer recognition program
  - Setting realistic goals
- Growing Funds & Resources
  - Soliciting corporate and government support
  - Encouraging member support
  - Fundraising initiatives relevant to the group's mission



## **SLIDE #14**

*TCC has consciously worked to face all of these challenges.*

*In order to make the most of the limited time of our volunteers, we have set the following priorities: effective and respectful management of volunteer time, energy, effort and intent; regular and relevant volunteer recognition programs; and setting realistic goals.*

*So that we can increase our funding and resource base, we have mandates to solicit corporate and government support, encourage member support, and pursue fundraising initiatives that are relevant to our mission. We have benefited from a Trillium grant that funded the development, design, printing and distribution of the first edition of the Patient Handbook in 2003. In 2004 our revenue was \$3,300, it climbed to \$11,000 in 2005 and last year we worked with a fund base of \$22,000. The printing and design of our brochures, booklets and quarterly newsletters accounts for between 50% and 75% of our total annual expenditures. We have had wonderful corporate support for our publications, but for the other expenses we have turned to an annual fundraising campaign directed at our members (we do not charge a membership fee or charge for our materials)*

# Overcoming the Challenges

- Building Credibility

- Taking every action seriously
- Establishing a Medical Advisory Panel
- Recruiting relevant and accredited experts
- Listening to and including the patient voice at every stage
- Developing and instituting an evaluation process



- "Getting on the Radar" and Staying There

- Fostering relationships with other cancer patient groups, support networks and patient education advisory committees
- Keeping the media informed
- Making the most of the internet
- Continuing to evolve following the trends of patient needs

## **SLIDE #15**

*We believe that we have been successful in building the credibility of our objectives, our processes and our materials, among clinicians, patients and caregivers. We recognized that this would be challenge from the beginning and we followed some very important steps along the way: we took every action and every project seriously; we established a medical advisory panel; we recruited relevant and accredited experts for our projects; we listened to and included the patient voice at every stage; and we have developed and instituted an evaluation process. For several years, even before the feedback survey project for the LID, we have been conducting member evaluation surveys. From these we have heard that patients enjoy being able to “pop in” online and discuss issues the questions with other patients who have similar challenges that are not always related to treatment but also to living well and managing life after a diagnosis of thyroid cancer. For non-profit volunteer groups, a strong evaluation process should be a priority for it is a very effective means of demonstrating the quality and relevance of the organization’s work to prospect financial supporters.*

*Finally, “getting on the radar” and, just as importantly, staying there. We have an active Liaison Committee through which volunteers foster relationships with other cancer patient groups, support networks and patient education advisory committees. We seek to expand our reach by increasing the distribution of our materials through cancer clinics, support centres and getting links to our website on relevant, reputable and credible sites. The media is an important tool in increasing awareness and we send out a press release on the day that the CCS releases their annual Canadian Cancer Statistics report, to draw attention to the ever increasing rate of incidence of diagnosis of thyroid cancer. This year, in April, our press release resulted in two articles to date, one in a local Sarnia paper and more recently in the Toronto Sun. We post all of our publications on our website, our listserv committee works tirelessly moderating the postings – all to make our resources as accessible as possible*

*In order to maintain our increasing visibility and recognizability, we must remain relevant and current. To do this we are committed to our members’ concerns and to staying current with the trends in diagnosis and treatment.*

# Article in Wellspring's CANCER SMART (pages 2 and 3 of the first issue)

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## Low Iodine Diet for Thyroid Cancer Patients

By Grace Wright, Volunteer, Thy'vours



Thyroid cancer patients across Canada preparing for radioactive iodine treatment or scanning now have access to an easy-to-follow nutrition guide thanks to the efforts of the Canadian Thyroid Cancer Support Group, Thy'vours.

In November 2006, the Thy'vours Low Iodine Diet was launched, marking the first initiative to define a nationally-recognized standard for a Low Iodine Diet (LID) – a diet which must be strictly followed in preparation for the radioactive iodine treatment commonly prescribed for thyroid cancer patients.

The importance of complying with a LID is significant: non-compliance may affect the accuracy of scanning procedures and possibly reduce the effectiveness of treatment. This is because thyroid cells absorb iodine more than any other cell in the body. Scanning and treatment procedures require that the body be temporarily starved of iodine, meaning that patients must almost entirely avoid any foods

that contain iodine. In fact, the daily iodine intake must be less than the equivalent found in 1/8 teaspoon of table salt.

However, table salt is not the only source of iodine in our diets, so compliance with a LID is a challenge for many patients. Most need access to specific nutritional information that pertains to iodine, and assistance in understanding how to alter food and eating habits.

To meet patients' needs and provide a standardized diet that would be applicable to patients country-wide, Thy'vours initiated an extensive research and consultation process with medical experts and representatives of government and industry. Drafts of the diet were reviewed by Thy'vours own Medical Advisory Panel, which represent experts in the fields of oncology, endocrinology, nuclear medicine, surgery and pharmacology.

The result is the first standardized LID that explains the purpose of the diet, the importance of sticking to it, and provides in detail a comprehensive list of foods that are allowed and those that must be avoided. Although most people connect iodine with salt, many are surprised at the range of other foods that contain iodine and therefore must be avoided, as shown in the diet on page 3.

Thy'vours is now receiving orders from physicians, specialists and nuclear medicine clinics across the country for copies of the Thy'vours Low Iodine Diet to distribute to their patients. ■

### Thy'vours Medical Advisory Panel 2006 -2007

**Ian Adam**  
Radiation Safety Officer,  
The Institute of Cancer Research

**Dr. Alice Y.Y. Cheng**  
Endocrinology and Metabolism,  
Assistant Professor (Adjunct),  
University of Toronto

**Dr. Wendy Chui**  
Registered Pharmacist, Canada Chemists  
Toronto North Medical Arts Centre

**Dr. A. Driedger**  
Professor of Nuclear Medicine/Oncology,  
University of Western Ontario  
London Health Sciences

**Dr. Daniel Drucker**  
Director, Bariatric and Best Diabetes Centre  
University of Toronto  
Samuel Lunenfeld Research Institute  
Mount Sinai Hospital

**Dr. Sheeren Ezzat**  
Professor of Medicine & Oncology  
Head, Endocrine Oncology  
Mount Sinai & Princess Margaret Hospitals

**George Gascoigne**  
Registered Pharmacist  
DeH Pharmacy, St. Catharines

**Dr. Gary M. Rodin**  
Head, Department of Psychosocial  
Oncology and Palliative Care,  
Princess Margaret Hospital, University  
Health Network  
Professor of Psychiatry, University of Toronto

**Dr. Irving B. Rosen**  
Professor of Surgery,  
University of Toronto Faculty of Medicine  
Department of Surgery,  
Mount Sinai Hospital

## Ontario Announces a Colorectal Cancer Screening Program

In January 2007, Ontario's Ministry of Health and Long-Term Care (MHLTC) announced plans for the development of a provincially-funded colorectal cancer screening program. It is the first screening program of its kind in Canada.

This initiative aims to decrease mortality from colorectal cancer through early detection. Colorectal cancer is currently the second leading cause of cancer death in Canada. When

detected early, however, 90% of patients can be cured.

The screening procedure involves the use of a Fecal Occult Blood Test (FOBT), an easy-to-use, at-home kit, which looks for the presence of blood in the stool, one of the symptoms of colorectal cancer. A positive FOBT (meaning that blood was found in the stool) does not mean that the person has colorectal cancer because there are other reasons for a positive

test. People with a positive FOBT would then be referred for other testing to determine its cause.

For people with no additional risk factors for colorectal cancer, the MHLTC recommends regular screening using the FOBT beginning at age 50.

By next year, FOBT kits will be available through family doctors, primary care clinics, Telehealth Ontario and, eventually, local pharmacies. Kits will be available free of charge. Cont'd on page 4

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## Food Guide for a Low Iodine Diet

Start LID on \_\_\_\_\_ and Stop LID on \_\_\_\_\_

| Foods and Ingredients to AVOID  | Foods and Ingredients that are ALLOWED  | Foods and Ingredients to AVOID  | Foods and Ingredients that are ALLOWED  |
|---|---|---|---|
| <b>Salt and Seasonings</b>  |   | <b>Dips &amp; Spreads</b>   |   |
| <ul style="list-style-type: none"> <li>iodized salt (all table salt in Canada)</li> <li>sea salt</li> <li>any food prepared with iodized salt</li> </ul>  | <ul style="list-style-type: none"> <li>fresh or dried herbs</li> <li>salt free spices and spice mixes</li> <li>vinegars</li> <li>non-iodized salt (bought in the USA)</li> </ul>  | <ul style="list-style-type: none"> <li>unsalted peanut butter or nut butters</li> <li>vegetable oils including soy or soybean oil</li> <li>unsalted, dairy-free margarine</li> </ul>  |   |
| <b>Fruits &amp; Vegetables (4 servings a day)</b>   |   | <b>Desserts &amp; Sweets</b>  |   |
| <ul style="list-style-type: none"> <li>rhubarb</li> <li>fruit or juice with red dye #3, such as maraschino cherries and red jellies</li> <li>juice with artificial colour</li> <li>potato peel or skin</li> </ul>   | <ul style="list-style-type: none"> <li>fruits and juices, except rhubarb and those coloured with red dye #3</li> <li>unsalted vegetables</li> </ul>   | <ul style="list-style-type: none"> <li>white or brown sugar, honey, maple syrup</li> <li>cocoa powder</li> <li>plain gelatin</li> <li>popcorns, jams and jellies without red dye #3</li> <li>marshmallows, hard candy, dark chocolate</li> <li>sorbet, unsalted meringues</li> <li>raisins, sesame seeds</li> </ul>   |   |
| <b>Fish &amp; Seafood</b>   |   | <b>Drinks</b>   |   |
| <ul style="list-style-type: none"> <li>all fish and shellfish</li> <li>all sea products such as nori, dulse, seaweed and kelp</li> <li>foods made with fish or seafood, such as fish sticks, dips, sushi, sashimi</li> <li>foods with ingredients such as alginate, algin, alginate, agar, carrageenan</li> </ul>   | <ul style="list-style-type: none"> <li>scorpe</li> </ul>  | <ul style="list-style-type: none"> <li>milk, cream or drinks made with dairy products</li> <li>soy milk</li> <li>juice and drinks coloured with red dye #3</li> </ul>   | <ul style="list-style-type: none"> <li>soft drinks (pop) without red dye #3</li> <li>coffee or tea without milk or cream</li> <li>homemade natural and rice milk</li> <li>fruit juice without red dye #3</li> <li>fruit smoothies made without dairy or soy products</li> <li>beer, wine and spirits if allowed by your doctor</li> </ul> |
| <b>Meat &amp; Alternatives (no more than 5 ounces or 150g cooked weight a day)</b>  |   | <b>Supplements &amp; Other</b>  |   |
| <ul style="list-style-type: none"> <li>any meat or poultry prepared with salt or sea salt, such as those treated in brine</li> <li>corned meats such as ham, bacon, corned beef, lox, wieners and luncheon meats</li> <li>soybeans or soy protein products such as soy sauce, soy milk and tofu (the exception is soybean oil)</li> <li>egg yolks</li> <li>salted nuts</li> </ul> | <ul style="list-style-type: none"> <li>fresh meats or poultry prepared without salt or brine (ask the butcher how the meat was prepared)</li> <li>wild game</li> <li>egg whites</li> <li>unsalted nuts</li> <li>lentils, beans and legumes</li> </ul> | <ul style="list-style-type: none"> <li>all medicinal and take-out food</li> <li>red dye #3 or erythrosine used in red/pink foods, drinks and medications (e.g. some cough medicine)</li> <li>medications or vitamins that contain salt or milk</li> <li>supplements with iodine or ingredients from the sea, such as glucosamine, chondroitin, coral or oyster shell calcium</li> <li>skin creams or disinfectants made with iodine such as betadine</li> </ul> | <ul style="list-style-type: none"> <li>medications, vitamins and supplements without salt, milk, sea ingredients, iodine or red dye #3 (check with your pharmacist)</li> <li>Do not stop taking any medications without talking to your doctor</li> </ul>   |
| <b>Grain Products (no more than 4 servings a day)</b>   |   | <b>All radiographic contrast media contains iodine. Thus, if you have had a CT/CAT scan with contrast, it may delay having a RAI scan or treatment by at least six months, due to the iodine content of the contrast.</b>   |   |
| <ul style="list-style-type: none"> <li>breads, cereals or crackers made with salt, egg yolks or dairy products</li> <li>salted pasta, rice or popcorn</li> </ul>  | <ul style="list-style-type: none"> <li>breads, cereals and crackers without salt, egg yolks or dairy products</li> <li>unsalted pasta, rice, rice cakes, matzo and popcorn</li> </ul>   |   |   |
| <b>Dairy Products</b>   |   |   |   |
| <ul style="list-style-type: none"> <li>all dairy products such as milk, cheese, butter, yogurt</li> <li>foods that contain dairy products or ingredients such as whey, casein and caseinate</li> </ul>  | <ul style="list-style-type: none"> <li>scorpe</li> </ul>  |   |   |

The Low Iodine Diet and other educational materials about thyroid cancer can be downloaded from the Thy'vours website at [www.thy'vours.org](http://www.thy'vours.org) or by calling 416.487.8257.

**SLIDE #16**

*(these are images of the article about the Thy'vors LID, featured in Wellspring's CANCERSMART newsletter)*

# Upcoming TCC Initiatives

- Developing French editions of our publications
- Developing resource lists for support and information accessible to LEP patients from other language communities
- Promoting a monthly 'neck check'
- Providing plain language reviews of articles and research results relevant to thyroid cancer diagnosis and treatment



## **SLIDE #17**

*While we have made noteworthy achievements, we continue to look for ways in which we can take our mission of support and education even further. We are constantly consider project ideas and evaluate them on the basis of priority and resources, in order to stay within the parameters of realistic goal setting. Among our list of upcoming TCC initiatives that we are evaluating are: the development of French editions of our publications; development of resource lists for support and information accessible to Limited English Proficiency patients; promotion of a monthly ‘neck check’, as currently endorsed by the American Association of Clinical Endocrinologists; and, providing plain language reviews of articles and research results relevant to the diagnosis and treatment of thyroid cancer.*

*As the demand for support and information increases in tandem with the rates of new incidences of thyroid cancer, we are constantly seeing that there is more that we can do. In the meantime, we believe our small successes might serve as an example for other volunteer patient-led groups who seek to provide support by drawing on their own past experiences and the desire to make it easier for others today.*

*Thank you.*



Thank you

[www.thryvors.org](http://www.thryvors.org)

Ontario Corporation Number 1506588 (January 29, 2002)  
Canada Revenue Agency BN 86306 9464 RR0001 (July 7, 2003)