

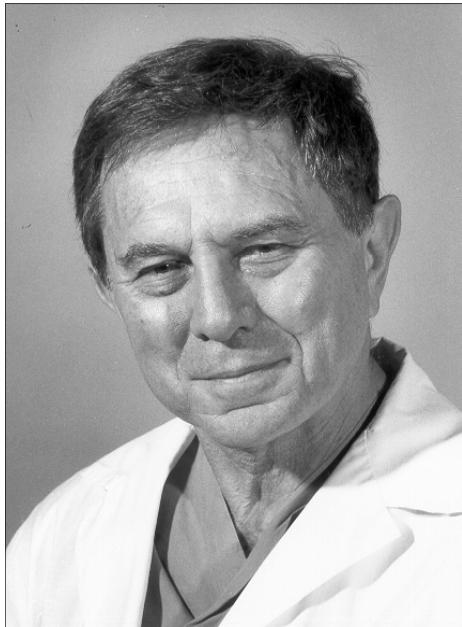


*Thyroid Foundation of Canada*  
**thyrobulletin**  
*La Fondation canadienne de la Thyroïde*

Volume 22, No. 3

Autumn 2001

## Thyroid lumps and bumps or Thyroid nodular disease



Irving B. Rosen, MD  
Professor of Surgery, University of Toronto

Lumps and bumps in the thyroid gland are more correctly entitled thyroid nodular disease (TND) which may be a result of low dietary iodine. Even in Canada where iodination of salt is the rule, TND is frequent. It has been estimated that palpable TND occurs in 5% of the North American population which means that about 20 million apparently normal people in North America have usually asymptomatic lumps in the thyroid area that can be felt, although the patients are frequently unaware of them.

In addition to this, ultrasound examination in people who have no lumps

by  
**Irving B. Rosen, MD**

that can be felt show a nodule 50% of the time. A thyroid nodule has to be about 1.5 cm. before it is palpable, but that depends on the patient's body build and location of the lump. The occurrence of a tumor and particularly a cancerous tumor occurring in a nodule is infrequent.

The word cancer is upsetting, so it is appropriate to note that cancer of the thyroid is "peculiar" because it is highly curable, does not usually recur, permits a normal life expectancy with demanding treatment and usually no impairment of function.

### Evaluation and treatment

Nodules can be solid or cystic, associated with normal, increased or decreased function, and can be tumors or non-tumors. If one were to make out a list of problems affecting the thyroid that cause nodules, it would list every possible condition of the thyroid. TND requires evaluation by a physician. This should consist of examination, thyroid blood tests, usually ultrasound examination, often a nuclear scan. The most important part of the evaluation lies in a fine needle aspiration biopsy (FNAB) in which a needle of a very fine caliber is inserted into the nodule and tissue is sucked back and sent off to a pathology lab for analysis.

If the patient has normal thyroid function and the FNAB shows no abnormalities, then the patient can be treated conservatively by taking thyroid medication although the needle biopsy should be repeated. Where the needle biopsy discloses the presence of a tumor or malignancy, then surgery is required. Where the nodule is sufficiently large to cause pressure problems in swallowing or breathing, or where the lump is so visible that the patient is embarrassed or anxious by its presence, surgery may also be necessary.

Nodules containing fluid are called cysts and may be cured by FNAB, but recurrent ones may also require surgery. Sometimes patients have discomfort in the head and neck area, and a physician will carry out a diagnostic ultrasound examination which will show an unsuspected nodule in the thyroid gland which cannot be felt. This is called an occult nodule which is usually harmless, and FNAB under ultrasound is then usually done for diagnosis.

### Conclusion

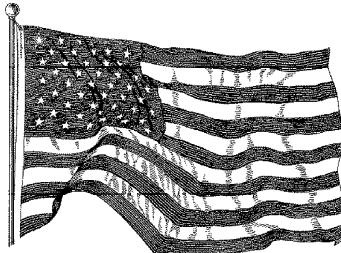
- TND is common and usually harmless. Even infrequent malignant nodules are easily cured.
- Every patient with a thyroid nodule should undergo an appropriate investigation by a doctor, and especially FNAB.
- Treatment of TND is, usually, by taking thyroid medicine. Surgery for TND is usually indicated for nodules

that are enlarging, that show tumor or malignancy on FNAB, or are the cause of the patient to feel anxious or cause distress.

Ed Antosz, editor, and Robert Volpé, medical adviser, felt that a column on 'lumps and bumps' that occur in the thyroid gland might help to clear up some concerns that the membership has expressed. I have been given the opportunity to help out in this regard.

If you have any questions that pertain particularly to lumps in the thyroid or TND, I would be pleased to hear about them and to try to provide answers.

*Irving B. Rosen, MD, FRCS(S), FACS, Professor of Surgery, University of Toronto; Department of Surgery, Mount Sinai Hospital; Co-Director Head and Neck Oncology Program, Mount Sinai Hospital; Emeritus Consultant in Surgery, Princess Margaret Hospital, Ontario Cancer Institute; Director, The Head & Neck Cancer Foundation.*



To our  
American  
neighbours, families  
and friends

Our thoughts and prayers  
are with all who lost  
relatives or friends during  
the September 11, 2001  
terrorist attack on the  
United States of America.



## The Neck Check: Can you do it?

**N**ow there is a simple self-exam to help Canadians check themselves for nodules and thyroid cancer. A palpable lump (nodule) on the thyroid gland could indicate the presence of cancer and should always be checked by a physician.

This neck examination was developed in 1997 by the American Association of Clinical Endocrinologists.

### To perform the neck check:

1. You will need a mirror and a glass of water.
2. Hold the mirror in your hand, focusing on the area of the neck immediately above the collarbone. Your thyroid gland is a butterfly-shaped gland in this area of the neck.
3. Staying focused on this area, tip your head back.
4. Take a drink of water and swallow.
5. As you swallow, look at your neck. Check for any bulges or protrusions (ignoring your Adam's Apple, of course!). Repeat the process as many times as you wish.
6. If you see a protrusion or bulge, call your doctor. You may have an enlarged thyroid gland or a nodule. The nodule should be checked to ensure that it is not malignant.

## Thyroid Nodules: Just the Facts

- ✓ A thyroid nodule is a 'bump' on the thyroid gland. Usually the nodule does not produce thyroid hormone, but at times it may produce excessive amounts causing hyperthyroidism.
- ✓ A palpable nodule should always be checked by a physician.
- ✓ Thyroid nodules are common to the general population.
- ✓ About 5% of adults have a palpable thyroid nodule.
- ✓ About 50% of people have a thyroid nodule detectable by ultrasound.
- ✓ Thyroid nodules are more common in women than in men.
- ✓ Thyroid nodules are probably caused by overstimulation by TSH, however, current research suggests that other factors are involved.
- ✓ Thyroid nodules often present no symptoms.
- ✓ Solitary thyroid nodules have a 5-10% chance of being malignant.
- ✓ Multinodular goitres have a 1% chance of being malignant.
- ✓ Nodules are biopsied using fine needle aspiration (FNA). Most nodules are easy to treat.
- ✓ Nodules occur more frequently in women than in men. However, a nodule in a man, or a child under the age of 14, is more likely to be malignant than if it is discovered in a woman.

# President's message

Thyroid Foundation  
of Canada and You!

Over the past 21 years, the president's message has been delivered to its members in each issue of *thyrobulletin* and has run on many themes. The messages have all been different but the underlying message remains the same: thyroid disease awareness, education, moral support to patients and research. These were our goals 21 years ago and they are our goals today.

- To awaken public interest in, and awareness of, thyroid disease;
- To lend moral support to thyroid patients and their families;
- To assist in fund raising for thyroid disease research.

The world has seen many changes during the past 21 years, and so has the Foundation: growth to 23 chapters across Canada's 10 provinces; an international foundation for thyroid disease and a research fund that provides annual grants for research. Have we reached everyone yet?

Statistics show that over 1.4 million people in Canada alone have thyroid disease – we presently have approximately 4000 members. You do the math!

The Thyroid Foundation of Canada is asking you to share with your family, friends and co-workers, your knowledge of thyroid disease and the work the Foundation continues to do “to make a difference in the lives of those who suffer from thyroid disease”. Ask them to support the Thyroid Foundation **as you do** by becoming a member and by donating to **your cause**. TFC would be pleased to accept your donations in monthly installments.

In the words of our late founder, Diana Abramsky, **“Just spread the word”**.

*May the coming Holiday Season  
bring you joy and happiness!*

Irene Britton/Irène Britton  
National President/Présidente nationale

Rejoice in the Holiday Spirit  
And may the New Year bring you Health  
Happiness and the Joy of Living

*The National Board and Staff*

# Message de la présidente

La Fondation canadienne  
de la Thyroïde et vous!

À cours des derniers 21 ans, le message des présidents se livra aux membres dans chaque numéro du *thyrobulletin* et passa par plusieurs thèmes. Les messages furent différents, mais le message sous-jacent reste pareil: conscience, éducation, soutien moral aux malades et la recherche sur les maladies thyroïdiennes. Ceux-ci étaient nos buts il y a 21 ans et ils le sont encore aujourd’hui.

- Éveiller l'intérêt du public et l'éclairer au sujet des maladies thyroïdiennes;
- Fournir un soutien moral aux malades et à leur proches;
- Aider à ramasser les fonds pour la recherche sur les maladies thyroïdiennes.

Le monde entier a vécu beaucoup de changement durant ces derniers 21 ans comme ainsi que la Fondation: la croissance à 23 sections à travers les 10 provinces du Canada; une fondation internationale des maladies thyroïdiennes et un fond de recherche qui finance des bourses annuelles. Avons nous atteintes tout les souffrant des maladies thyroïdiennes? Les statistiques indiquent qu'il y a environ 1,4 millions de personnes atteintes de cette maladie au Canada – nous avons présentement à peu près 4000 membres. Faites les mathématiques!

La Fondation canadienne de la Thyroïde vous demande de partager avec votre famille, vos amis et vos collègues, vos connaissances de cette maladie et celles du travail de la Fondation qui “fait une différence dans la vie des souffrant des maladies thyroïdiennes”. Demandez leurs de soutenir la Fondation canadienne de la Thyroïde **comme vous le faites**, en devenant membre et en donnant à **votre cause**. La FCT se fera un plaisir d'accepter vos dons mensuels.

Dans les mots de Diana Abramsky, notre feu fondatrice, **“propager la parole”**.

*Que l'approche du temps des fêtes vous apporte la joie et le bonheur!*

Irene Britton/Irène Britton  
National President/Présidente nationale

Durant la Saison des Fêtes nous vous  
Souhaitons la Bonne Santé, le Bonheur  
Et la Joie de Vivre

*Le Conseil National et son personnel*

# **Thyroid Foundation of Canada**

## **La Fondation canadienne de la Thyroïde**

Founded in/Fondée à Kingston, Ontario, in 1980

### **Founder**

*Diana Meltzer Abramsky, CM, BA  
(1915 – 2000)*

### **Board of Directors**

#### **President of each Chapter** (currently 23)

**President** – Irene Britton (NB)  
**Secretary** – Darlene Ibey (ON)  
**Treasurer** – Terry Brady (ON)

#### **Vice-Presidents**

**Chapter Organization & Development** – Joan DeVille (ON)

**Education & Research** – Lottie Garfield (ON)

**Publicity & Fundraising** – (Vacant)

**Operations** – Venette Godbout (NB)

**Past President** – Arliss Beardmore (BC)

#### **Members-at-Large**

*Marc Abramsky, Ed Antosz, Ellen Garfield, Nathalie Gifford,  
Marvin Goodman, Rita Wales*

### **Annual Appointments**

**International Liaison** – *National President* – Irene Britton

**Legal Adviser** – Corinne A. Godbout, BBA, LLB

**Medical Adviser** – Robert Volpé, MD, FRCPC, MACP

Thyroid Foundation of Canada thanks Health Canada for its financial support.

Thyroid Foundation of Canada is a registered charity  
number 11926 4422 RR0001.

La Fondation canadienne de la Thyroïde remercie Santé Canada pour son support financier. La Fondation canadienne de la Thyroïde est un organisme de bienfaisance enregistré numéro 11926 4422 RR0001.



# *Thyroid Foundation of Canada*

# **thyrobulletin**

*La Fondation canadienne de la Thyroïde*

ISSN 0832-7076 Canadian Publications Mail Product Sales Agreement #139122

**thyrobulletin** is published four times a year: the first week of May (Spring), August (Summer), November (Autumn) and February (Winter)

**Deadline for contributions for next issue: December 15, 2001**

Le **thyrobulletin** est publié quatre fois par année: la première semaine de mai (printemps), août (été), novembre (automne) et février (hiver).

**La date limite pour les articles pour le prochain numéro: le 15 décembre, 2001**

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### **Please note:**

The information in *thyrobulletin* is for educational purposes only. It should not be relied upon for personal diagnosis, treatment, or any other medical purpose. For questions about individual treatment consult your personal physician.

### **Notez bien:**

Les renseignements contenus dans le *thyrobulletin* sont pour fins éducationnelles seulement. On ne doit pas s'y fier pour des diagnostics personnels, traitements ou tout autre raison médicale. Pour questions touchant les traitements individuels, veuillez consulter votre médecin.

### **The objectives of the Foundation are:**

- to awaken public interest in, and awareness of, thyroid disease;
- to lend moral support to thyroid patients and their families;
- to assist in fund raising for thyroid disease research.



### **Les buts de la Fondation sont:**

- éveiller l'intérêt du public et l'éclairer au sujet des maladies thyroïdiennes;
- fournir un soutien moral aux malades et à leur proches;
- aider à ramasser les fonds pour la recherche sur les maladies thyroïdiennes.

# Thyroid cancer meeting

Members of Kingston Area Chapter (KAC), Thyroid Foundation of Canada, were approached by six thyroid cancer survivors (one of whom, Kim McNally, is a KAC board member) asking the Foundation to work with them in providing educational material and support for thyroid cancer patients. As a result, the Foundation organized a meeting in Toronto on Saturday afternoon, September 29, 2001, at Mount Sinai Hospital, to try to identify how thyroid cancer patients might better be

served. In attendance were six representatives from the Foundation, five thyroid cancer survivors, Dr. Irving Rosen, surgeon at Mount Sinai, Dr. Robert Volpé, medical adviser to the Foundation and representatives from Abbott Laboratories, CancerConnection Canadian Cancer Society, genzyme Canada Inc., The Head & Neck Cancer Foundation and Theramed Corporation – 22 people in all. Beth Rajnovich of the cancer survivors group, acted as chair.

Following a wide ranging and informative discussion it was agreed that

a small representative group would work on assembling resource material and a distribution strategy, prior to a second meeting of the group as a whole to be held early in the new year.

Patricia Sharkey, a member of the cancer survivors group, is to be commended for her work in assembling an extensive information package that was distributed with the agenda prior to the meeting.

Thanks, also, to Dr. Rosen and his secretary, Margaret Allen, for arranging for the meeting room and refreshments.

## Comments for thyroid cancer meeting

From the beginning, and when I started to correspond separately with some women from Ontario who met on the ThyCa listserve, it has been my hope to get more information about thyroid cancer out to the public, and most importantly, to anyone recently (as well as in the past) diagnosed with thyroid cancer – where to turn, etc.

Immediately I felt that the already existing Thyroid Foundation (of which I have been a member of the Kingston chapter board for a number of years) was the most obvious first stop on this endeavour. It was my hope that we could utilize the existing manpower, web site and materials/literature available through the Foundation to create in-depth resources pertaining to thyroid cancer – facts, symptoms, radioactive iodine (RAI), low iodine diet (LID), fears.

As well, and through group discussions, it was felt that one of the best ways of getting this information out, was through the front-lines, via the patients' doctors. As a result a survey was set up and comments were invited. As it turns out we have great interest from some of the physicians.

I felt that one of the most crucial ways of getting information to patients was through one-on-one counselling.

Along this thread, and having been a volunteer with CancerConnection for four years now, I realize the importance for new patients of having somewhere to turn. I receive approximately 10-12 referrals per year matching me with recently diagnosed thyroid cancer patients. Many of these callers are upset,

by  
**Kim McNally –  
Thyroid Cancer Survivor**

despondent, scared and uneducated about thyroid cancer and understandably so. Often they are not satisfied with the level of treatment and care provided them by their doctors. They are seeking immediate answers to their concerns and have many questions about their disease, including the chance of it spreading, concern over their health – lack of energy, depression, over all feelings of unwellness, etc. I personally feel that this immediate (calls are returned within 24 hours) and personal attention to patients is of great importance in helping ease their fears. Being able to TALK to someone who HAD thyroid cancer is truly appreciated by the caller.

Therefore I feel it is important to remind/educate the public about:

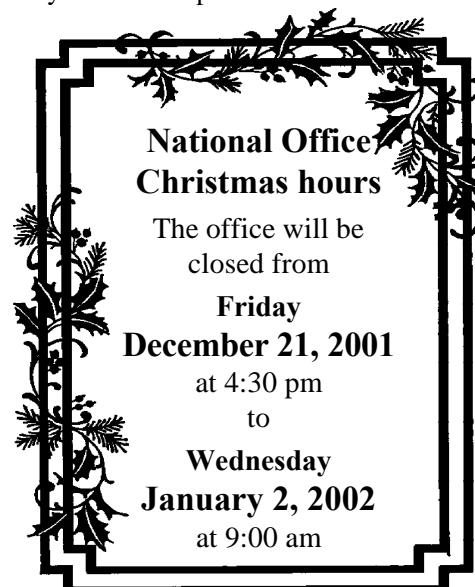
- the Thyroid Foundation and *thyrobulletin* and its inclusion of thyroid cancer information;
- the existing support system of CancerConnection available to match callers.

I would like to see developed an information package for doctors (specifically endocrinologists and thyroid specialists) to give to newly diagnosed patients, which may include:

- information on thyroid cancer (as mentioned above);

- information on the Thyroid Foundation and the literature it provides on thyroid cancer;
- the 1-800 phone number for CancerConnection;
- commonly asked questions & answers for thyroid cancer patients;
- other relevant information/literature.

These are just my thoughts for now. I am sure I will have more to add once the meeting is underway, but in the meantime, I am just really excited about us all sitting around the table and meeting each other face to face. I have no idea what to expect as far as the outcome of the meeting, but again, I want to thank all of you for your interest and support in implementing 'whatever it is we accomplish' as we journey along the thyroid cancer path.



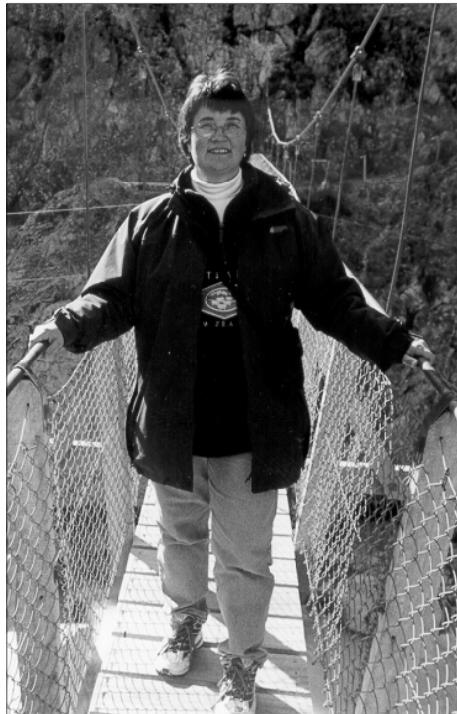
# My thyroid cancer story

During the summer of 1999, I discovered that I had a lump on my throat. My family physician assured me that these lumps are usually benign, but sent me for an ultrasound. I suspected something was wrong when the ultrasound technician left to get the radiologist, and I heard the two of them whispering. They were counting, up to eight or ten I think. Eight or ten what??!! They didn't tell me anything, of course. That gave me something to think about while I waited two months to see an endocrinologist who told me that I had a multi-nodular goiter, and that one of the nodules was quite large. He asked if I had ever been exposed to x-ray radiation as a child or teenager, which I hadn't. Later I found out that this is often the cause of thyroid cancer. The endocrinologist told me that I would have to have the left lobe of my thyroid removed and sent me to see a general surgeon to do a fine needle aspiration biopsy. The results indicated "suspicious" and the surgeon set a date for surgery, but assured me 'this could wait – it's probably benign.' Further, he said, even if it is malignant it's no big deal because "if you have to get cancer the thyroid is the place to get it." Thyroid cancer is slow growing and relatively easy to treat.

Later I found out that there is controversy among physicians as to whether a total thyroidectomy should be done in a case such as mine, as opposed to a partial, or lobectomy. But my surgeon was not a thyroid specialist, seemed nervous about the risks involved in total thyroidectomy, and didn't seem to believe that I had thyroid cancer. So he took the conservative route and removed only half.

The surgery wasn't that bad – a little scary but not all that painful as the nerves in your neck are severed and don't grow back for a year or so. We had also been told that there was no lymph node involvement – if the cancer spreads it usually goes to the lymph nodes first. Then I went back to see the surgeon a week post-surgery and was devastated to hear the word "carcinoma" as he read the pathology report. That's about all I got out of what he said except that I needed iodine radiation treatment, but before that another operation to take out the other half of my thyroid. Because the thyroid

By  
**Dianne Dodd**



Dianne Dodd  
Ottawa Area Chapter

naturally absorbs iodine, a dose of irradiated iodine is administered to kill all remaining thyroid tissue left after surgery.

But at that moment, all I could think about was having to have a second surgery. Just the thought of opening up an incision that was not yet healed made me shudder. Sitting alone in his office I wished I had brought my husband or a friend along for support, but of course they don't tell you ahead of time, "Oh, we're going to tell you that you have cancer so bring lots of emotional support." That's the insidious thing about having cancer! You feel that they're taking away your health a little bit at a time. The bad news comes in slow increments and undermines your confidence in anyone who says, "Don't worry, it's probably nothing."

My second surgery seemed like déjà vu or perhaps a recurring nightmare. Although I had next to no voice left, which worried me greatly at the time,

about six months later my voice returned to normal. Still I hadn't been sick that long and there were visits, phone calls from people I hadn't heard from in years, cards, flowers, etc.

My surgeon could only tell me that I had to become hypothyroid for the treatment and that I would feel really sick (boy, was he right about that!!!) but he didn't know how long I would have to be off medication. His office made an appointment for me at the Cancer Clinic but I had to wait three weeks after surgery. I called and tried to find out how long I would need to be off medication before the RAI (radioactive iodine) but the Cancer Clinic would not tell me anything until I had my initial visit. So I waited, feeling frustrated and scared. I felt I had fallen through the cracks in the medical system.

Finally, I went to the bright shiny offices of the Cancer Clinic at the Ottawa General Campus. All the stops were pulled to make me feel warm and fuzzy. My husband was with me, and they even had a partition in the doctor's office so that patients had privacy when being examined, while one's partner or friend could be there to ask questions or absorb information. This was all based on the theory that patients are stressed out and don't listen well when being told they have cancer. But, by the time I got there, I already knew I had cancer and had absorbed that information at a time when I had least expected it. Now I was being offered counselling! I remember thinking "Oh, that's just for people with real cancer, people who have to have chemo, lose their hair and worry about dying." I had no idea then how much I would need help later on.

At three weeks post-surgery I was so hopeful that I would be immediately admitted to hospital for my RAI that I had already packed my bag. I wanted to get it over with and get back to my life. I was devastated to find out that it took SIX weeks to become sufficiently hypo to have the treatment. I still had three weeks to go! By the end, I felt like I was dying. I needed to take Gravol and Tylenol every day to control the horrible headaches and nausea. I was sleeping a lot of the time

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and gradually getting more and more depressed. My skin turned gray, my eyes got puffy, and I went through a period of insomnia. My reflexes slowed down so much that, not only could I not drive, but I could barely speak or even think clearly. By the last week I couldn't have a conversation with anyone or even concentrate enough to read. I just sat in my recliner and stared out the window waiting to go to the hospital.

By comparison with the hypo-hell, the RAI was uneventful enough, though 24 hours in isolation was alienating. Everybody was being so careful with the dose of irradiated iodine yet I had to drink it! Everything in the room was covered in plastic, including the phone, and the floor was covered in paper. The nurses wouldn't come into the room and left food trays outside my closed door. When my husband came to get me they almost wouldn't let him in!!

When I came home I had to be careful not to contaminate my family. My husband took the children away for a few days and I stayed mostly in my room for a week. The hardest thing was not being able to kiss or hug my youngest child who was only seven then. My husband was also nervous for a while about my preparing food, so I really felt like a leper. All of these precautions are of course reasonable but they are hard to handle when you're very sick and depressed. Everything looked so hopeless at that point, and I had withdrawn so much from my husband and kids, that I felt like a Martian in my own home.

After three weeks of taking Synthroid I began to feel human again, but I knew I would have to go back to hypo-hell for a post-treatment scan to confirm that all the thyroid cells were gone. While the second hypo period was, in some ways, not as bad – it was still awful. By the time I went for the diagnostic scan in November my husband and I were barely speaking to each other.

Fortunately, my diagnostic scan was 'clean'. I no longer had any thyroid cancer left in my body! But I was much too sick and too sad and worn down by illness to celebrate. I went back on Synthroid, went back to work and waited to feel normal again. But like most people, it took a year before I was really well. I was tired and felt like I was still hypo, even though my TSH was normal. Actually, it was below

normal, as thyroid cancer patients need to have a suppressed TSH to prevent recurrence. Some days it felt like I was reliving the nightmare – it would suddenly come back to me – the way I had felt when hypo. I tried a combined dose of Cytomel and Synthroid, but became so hyperthyroid that I had tremors and couldn't concentrate. Hyper symptoms are surprisingly similar to being hypo, except one feels very anxious and restless while experiencing extreme fatigue and there can be violent mood swings, insomnia and other distressing symptoms.

I was still struggling, angry and depressed when I found an Internet support group for survivors of thyroid cancer. At first, I spent hours on line and soaked up information like a sponge. It was an immense relief to talk to people who understood how I felt. My family had lost their patience with the Mom who didn't seem to ever get better. They didn't want to hear about it anymore. But I wasn't well enough yet to put it behind me. The amazing thing about the support group was that people could rant and rave and bash their families, or their doctors . . . really just say anything at all and someone would give them a sympathetic, helpful response.

Finally, I realized I was suffering from a lingering depression – a common side effect of thyroid cancer treatment. With help from my family doctor, a health counsellor, the support group as well as some special people in my life, I recovered and regained my energy. Everyone is unique, but for me part of recovering meant acknowledging my own feelings. While well meaning relatives and physicians took comfort in the treatable nature of thyroid cancer, I felt they dismissed my illness as not very serious. And I still get angry when I hear someone refer to thyroid cancer as the good cancer. As we say in our support group, there is no such thing as a good cancer. The treatment process is lengthy and stressful for patients as well as their families. In one sense I was very lucky – I had a treatable form of cancer, only had to have two hypo-hells and one RAI (some people have more) and I'm not likely to have a recurrence. On the other hand having cancer forced me to confront some scary realities, re-evaluate my values, priorities and relationships.

Although painful, it wasn't all bad. I did learn to take care of myself better.

Now I conserve my energy for the important things, I cherish the people who supported me while I was ill and I even do more fun things.

The other thing I learned was the value of support throughout the treatment process. In my experience medical personnel, specialists in particular, provide minimal, sporadic information. The patient never gets the big picture and that makes it harder for individuals, as well as their families/caregivers, to cope. Most of the information I got came from books, the Internet and my support group. Having met online, I am now part of a small group of Ontario thyroid cancer survivors who try to help new patients cope with the disease by providing information and support and I volunteer with the Thyroid Foundation of Canada and CancerConnection, talking to newly diagnosed people.

## In Memoriam



**Diana Hains Meltzer Abramsky  
1915 - 2000**

*A loving wife, mother and grandmother.*

Member Order of Canada  
Founder Thyroid Foundation of Canada

Passed away October 9, 2000

*Her good deeds and vision benefitted all humanity.*

The unveiling of Diana's headstone took place on Sunday afternoon, September 23rd.

# Chapter news



Margaret Evans, PhD, Founder of Kitchener/Waterloo Area Chapter

## Kitchener/Waterloo

Congratulations to Margaret Evans, PhD, Founder of Kitchener/Waterloo Area Chapter in 1982. Dr. Evans recently received a City of Kitchener Seniors Award of Distinction in the category of health and fitness.

When Dr. Evans was diagnosed with Graves' disease she resolved not to let the disease run her life. Two years later she started the Kitchener/Waterloo Area Chapter of the Foundation to provide support and information to others with thyroid disease.

Dr. Evans served as the chapter's first president for five years and at present, single-handedly, answers all the telephone calls on the chapter's 24-hour help-line and mails thyroid literature to all those in need of information.

## London

London has a position open on its board for a volunteer. Please help us so that the chapter remains strong and able to help the many thyroid patients and families who are looking for information and support. **Please help us so that we may help others. Call 519-649-5478**

## Kingston

Congratulations to Douglas Clarke, pharmacist, Loblaws Pharmacy, who recently completed the certification process offered by the Canadian Diabetes Association. Doug is now a Certified Diabetes Education-Pharmacist, and leads the monthly diabetes information sessions as well as our monthly thyroid discussion group.

On September 27, 2001 members of Kingston chapter surprised Margaret Burdsall, chapter president with a birthday luncheon on her 80th birthday. Twenty four people were present including chapter members, national office staff, volunteers and national board members. Everyone was pleased to see Jane Bumstead Pinco of Calgary, Margaret's daughter and a former Kingston board member, and her seven-month old daughter Abbey.

Irene Britton national president who was visiting the national office, was a welcome guest at the luncheon. During the week she was also able to participate in the Sunday afternoon Loblaws discussion group, assist at the chapter's bingo and attend the thyroid cancer meeting in Toronto.

## Montreal

The Montreal chapter board members met on several occasions to plan for the new season. Entertainment books are being sold as a fundraiser. To buy a book, or to sell books, please contact us at **514-482-5266**. **We can use all the help we can get.** The information line continues to be very busy. The calls are returned as soon as possible. Looking forward to meeting old friends and new at the upcoming meetings.

## Ottawa

Dianne Dodd and Margaret Lafrance, whose stories appear in this issue, were two members of the *Patients Panel* who presented their experiences at the April 17, 2001 public education meeting of the Ottawa chapter. These *Patient Panels*, so brilliantly moderated by Dr. Timothy O'Leary, are extremely rewarding education sessions.

## Toronto

Toronto chapter members were pleased to learn that Natalie Kotowycz, a Toronto chapter volunteer, was accepted into the Medical School at the University of Western Ontario, London, Ontario. We are particularly pleased since Natalie has received two summer scholarships from the Foundation. Her interest and activities on behalf of the Foundation have been very much appreciated. We wish her the best of luck in her career.

## Gertrude Abush

Toronto chapter members and the national board were deeply saddened to learn of the death in July 2001, of Gertrude Abush. Gertrude was a dedicated, active member as well as a founding member in 1981 of Toronto Area Chapter. She continued to be active, served as treasurer for many years and membership chair, and also served on the national board. We all admired her courage and fortitude when facing adversity in her life. Our heartfelt condolences to her husband Max and family. She will be sadly missed by all.

## NOTICE TO ALL MEMBERS

Your membership in the Foundation expires on the date that is printed on the address label on your *thyrobulletin*.

Please use the **Membership/Donation Form** on page 15.

You may renew early – and for one or two years! You will be credited with renewal on the date that you are due to renew.

**... Donations are always welcome.**

# My experiences with hypothyroidism

I am writing about my experiences when I suffered from misdiagnosed, and therefore, untreated hypothyroidism from 1977 to 1984: a long time ago but it is still fresh in my mind.

I want to mention here that I am aware that symptoms of hypothyroidism can sometimes be mistaken for other medical problems. Therefore what follows is not a criticism of the medical profession and any comments I make about how the symptoms were treated at the time, by the doctors I saw, are just part of my story. I think too, what made the problem more difficult to diagnose was the fact that during this period I didn't suffer from constant severe hypothyroidism and in fact would feel reasonably well for maybe a couple of months at a time. To this day, I have what my G.P. calls a 'tricky' thyroid, as I need to have my T4 and TSH levels checked every 3 months and the medication adjusted accordingly.

To my story. In the mid-nineteen seventies, my husband and I had bought a new house. I was working for the federal government and managed to get out of the secretarial field and into administration. The mid-seventies also saw the beginning of the fitness boom and I had joined this 'boom'; gave up smoking and took up jogging.

In spite of all these positive lifestyle changes I noticed I seemed to be constantly tired. At work, by the afternoon, I had to drink black coffee to keep myself awake, in spite of having slept for about 9 hours the night before. In time, I found I was unable to concentrate, was becoming very forgetful and the simplest tasks were becoming more and more difficult to perform. I put this down to burnout or boredom, and after talking it over with my husband I decided to quit my job, take a year's sabbatical and see if a complete career change would help. Little did I know at the time that the one year sabbatical would turn into seven very unpleasant years.

Three months after I had stopped working, I woke up one morning feeling extremely lethargic and every movement felt as though I was trying to move around in water. As well, my face, hands and stomach were swollen. I went to see my family doctor who told me that it was

by  
Margaret Lafrance



Margaret Lafrance  
Ottawa Area Chapter

probably a mild kidney infection. The 'kidney infection' lasted a couple of months, then one day I noticed that I was having to urinate frequently, the swelling was going down and I seemed to have more energy.

Unfortunately a few weeks later the same thing happened, only the swelling was more pronounced to the point where I was unable to do up my pants over my very swollen stomach. I again went to see my G.P. who looked something up in a manual he had on his desk and said it was probably caused by unusual hormonal changes.

I am going to describe some of the symptoms I suffered during this seven year period and how they affected my life:

- Depression, anxiety, emotional instability, irritability. At times I thought I was losing my mind.
- As a result of the metabolic changes in my body, I developed very bad breath. This and my behavioral changes had a profound effect on our

relationship. As a result our sex life was non-existent.

- Being aware of suffering from halitosis absolutely devastated me as I saw this as another barrier preventing me from being employable. It also made it difficult for me to socialize with friends and I, therefore, became socially isolated.
  - I suffered from the classic symptoms of fatigue. At the time, I felt as though I was carrying a 50 lb weight on my back and any effort at physical activity left me exhausted.
  - I was always cold.
  - I would wake up every morning with numbness and tingling in my hands and wrists. I assumed I must have been somehow lying on my hands in my sleep to cause this problem.
  - My balance and coordination were poor. I would frequently bump into people while walking along the street.
  - I frequently forgot dates, times and had difficulty in concentrating.
  - Disorientation was another symptom. I would come out of a downtown building and have no idea where I was, or what direction to go in.
  - My voice was often hoarse and at times my speech was slow and slurred. Friends told me later that they thought I had developed a drinking problem.
  - I had menstrual problems.
  - Constipation
  - My face was pale and puffy, my hair thin and dry.
  - I had frequent bladder and vaginal infections, colds and 'flu.'
  - At each annual visit to my eye doctor he would suggest that I see my family doctor as a white ring around the cornea of my eyes suggested I had high cholesterol levels.
- During these years my original doctor moved away and the G.P. who took over from him, prescribed diuretics for the fluid and antibiotics for the infections. He also sent me to see an ear, nose and throat

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# Chapter coming events

Free admission – everyone welcome

## Burlington/Hamilton

**Location:** Joseph Brant Memorial Hospital, Bodkin Auditorium.

- Tuesday November 6, 7:30 pm. **Dr. Barry Hunter**, Obstetrician/Gynaecologist. Topic: *Childbearing years through menopause*.

For information call (905) 637-8387

## Kingston

**Location:** Ongwanada Resource Centre, 191 Portsmouth Avenue

- Tuesday November 20, 7:30 pm. **Dr. Robyn L Houlden**, Endocrinologist. Topic: *What's new with thyroid disease research?*.

For information call (613) 389-3691

**Location:** Loblaws Market, Upstairs, Kingston Centre

- Fourth Sunday of each month from 3:00 - 4:00 pm – monthly thyroid discussion led by Doug Clarke and Bozica Popovic, pharmacists, Loblaws Pharmacy. Thyroid literature available. Elevator.

For information call (613) 530-3414

## Kitchener/Waterloo

**Location:** The Community Room, Albert McCormack Arena, 500 Parkside Drive, Waterloo

- Tuesday November 20, 7:30 pm. **Dr. Cameron Purdon**, Endocrinologist, Medical Adviser to K-W chapter. Topic: *Ask our medical adviser – bring your questions*.
- Tuesday February 12, 2002, 7:30 pm. **Dr. M. Gulam**, Endocrinologist. *Thyroid cancer*
- Tuesday April 9, 2002, 7:30 pm. **Dr. Rick Dubeau**, Nuclear medicine and thyroid disease.

For information call (519) 884-6423

## London

**Location:** London Public Library Auditorium, 305 Queens Avenue

- Tuesday November 20, 7:30 pm. **Dr. R. Holliday**, Surgeon. Topic: *Role of surgery in thyroid disease*.

For information call (519) 649-5478

## Montreal

**Location:** Livingston Hall, Montreal General Hospital

- Monday November 26, 7:30 pm
- Wednesday February 13, 2002, 7:30 pm
- Monday March 11, 2002, 7:30 pm
- Saturday April 13 to Tuesday April 16, 2002. **6th Annual Art Exhibition and Sale**

For information call (514) 482-5266

## Irish Blessing

May there always be work for your hands to do;  
May your purse always hold a coin or two;  
May the sun always shine on your windowpane;  
May a rainbow be certain to follow the rain;  
May the hand of a friend always be near you;  
And may God fill your heart with gladness to cheer you.

### My experiences ... con't from page 9

specialist for my halitosis problem. He, of course, found nothing wrong.

The first gynaecologist I went to prescribed medication for my menstrual problems and said I was run down. When he retired the new gynaecologist listened to my symptoms and prescribed medication for my menstrual problems.

In the spring of 1984, I was taking a CPR course (in spite of having difficulty in following what I was supposed to do). As the CPR instructor was taking my pulse she asked me if I was unwell, as my pulse was extremely slow and I was very pale. Somehow this comment triggered something in my sluggish brain. I again went to see my doctor and insisted there really was something wrong with

me. He looked at me and touched my puffy face, then sent me for a blood test. This confirmed my thyroid was very underactive. At last a member of the medical profession believed me; he apologized profusely and admitted he thought my symptoms were 'all in my mind'.

How wonderful I felt after being on the medication for a few months! I felt that I had finally got my life back. Unfortunately it was too late to save my marriage and my husband and I became legally separated.

The mid-1980s was a period of recession and a shortage of work. Unfortunately because of my age and outdated skills, I had to concentrate on returning to the secretarial field in the

federal government. After taking a computer course, three years later I finally found permanent employment as a secretary in a federal government department, only to be laid off one year later!

There is no doubt that living with untreated hypothyroidism for seven years, was instrumental in breaking up my marriage. As well, the inability to hold down a job during this period, resulted in no job pension and a reduced Canada Pension income.

However, I consider myself very lucky that I suffered from an easily treatable disease and that I am now a happy, fit, healthy senior citizen with many friends and interests, and still capable of working part-time.

# Radioiodine: advice to patients

**R**adioactive iodine or radioiodine is to thyroid disease what cardiac catheterization and open heart surgery are to heart disease. It is widely used by thyroidologists in both evaluating and treating patients who have thyroid problems. To those of us who use it extensively on a day-to-day basis, radioiodine is an indispensable tool. However, for the patient who is unfamiliar with it, taking a radioactive chemical is often met with anxiety.

Radioiodine is iodine that has been made radioactive, but in the body it behaves exactly like iodine that is not radioactive. It is not a new discovery, having first been used in the 1930s. Although several types of radioiodine exist, only two types are given to patients. Radioiodine-123 is used in diagnosing thyroid disease and it is given to measure thyroid iodine uptake (activity of the gland) and to perform thyroid scans. Radioiodine-131 is used in treating patients who have hyperthyroidism and in the treatment of thyroid cancer.

Radioiodine is administered as a capsule or in a glass of water. After it is swallowed by the patient, it goes into the blood from which it is concentrated almost exclusively by the thyroid gland. Since it does not remain in other tissues, the radioiodine **not** taken up by the thyroid gland is rapidly eliminated by the kidney and excreted in urine.

## Radioiodine-123 for diagnosis

Radioiodine-123 is used exclusively for diagnosis and exposes the patient to a very low amount of radiation (far less than a chest x-ray). Because of its short half-life, virtually all the radioactivity is eliminated from the body within two days.

Half-life is a term used to describe the spontaneous disappearance or 'decay' of radioactive materials. The half-life of radioiodine-123 is 13 hours. After 13 hours, one-half of the radioiodine-123 has disappeared or 'decayed'. The half-life of radioiodine-131 is approximately 7 days.

As with x-rays, radioiodine-123 is not given to pregnant women, and nursing mothers are told to discard milk for two days after the radioiodine-123 is administered. Measuring thyroid radioio-

by  
**H. Jack Baskin, MD**

dine-123 uptake is frequently important in diagnosing certain types of thyroiditis and in differentiating Graves' disease, where the radioiodine uptake is high, from other types of hyperthyroidism, where the uptake may be low. The thyroid radioiodine uptake determination is also needed before treating patients who have Graves' disease.

Thyroid scans using radioiodine-123 provide not only a picture of the thyroid gland but also show the function of various regions within the gland. This **cannot** be determined by regular x-rays, thyroid ultrasound, or CAT or MRI scans. A radioiodine-123 scan is critically important in evaluating thyroid nodules, since nodules that take up radioiodine (referred to as 'hot' nodules) are not malignant and do not require a needle biopsy, while most other nodules will need a needle biopsy.

Frequently, thyroid scans are performed with another radioactive material called Technetium-99m. Technetium scanning is preferred by some physicians because it can be performed in a few hours on a single day. It is not as good for evaluating thyroid nodules, because it does not distinguish as well between those that are benign or malignant.

## Radioiodine-131 and the treatment of disease

Although radioiodine-131 is still used to scan patients with known thyroid cancer, its primary use is in the treatment of thyroid disease (both hyperthyroidism and thyroid cancer). Since its first use before WW2, it has become the treatment of choice for Graves' disease. In the past 50-years, over one million people have been treated with radioiodine-131, and, to date, no known side effects have occurred. The frequency of thyroid cancer, leukemia or other types of cancer is not increased in patients who have received radioiodine therapy, nor has there been an increase in birth defects in

children of women who have received this form of treatment.

In fact, few medications or treatments used in medicine have a better safety record than radioiodine-131. The only time it cannot be given is in pregnancy. If pregnancy is a possibility, a pregnancy test can be performed prior to taking radioiodine, and patients are advised not to get pregnant for three to six months after treatment. Infertility is not increased by radioiodine-131 treatment. In fact, the relative infertility caused by the patient's hyperthyroidism will often resolve after therapy when thyroid hormone levels return to normal. People who felt they *did not need to worry about birth control* may find themselves very fertile after treatment. Therefore, it is recommended that all patients use birth control for at least three months after radioiodine-131 treatment.

## Guidelines after treatment

Precautions following treatment are few. Since the iodine that does not go to the thyroid is eliminated by the kidney, the urine will have some radioactivity for a few days after treatment. Drinking 3 to 4 extra glasses of water on the day you take the radioiodine helps flush the radioiodine from the body.

So that others are not exposed unnecessarily to small amounts of radiation, patients should minimize close contact with pregnant women and young children for three days following treatment. To avoid contamination of others in the household, patients should use separate bath linens. Patients should also refrain from kissing during these three days, since there will be small amounts of radioiodine in the saliva. Rinsing the sink and flushing the toilet twice after use also helps decrease the risk of contaminating others.

Because radioiodine-131 is secreted in breast milk, mothers should not nurse following treatment until the milk has been tested and is free of radioactivity. This may take many weeks since, unlike radioiodine-123 used for scans, discussed above, the half-life of radioiodine-131 used for treatment of hyperthyroidism is much longer.

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## What to expect

Patients treated for Graves' disease are cautioned not to expect immediate results. Virtually nothing happens during the first month after treatment, and blood tests do not improve. Patients should get as much rest as possible, and stay on an adequate diet during this time as they are still hyperthyroid. Beta blockers such as Inderal (propanolol) block the effects of excess thyroid hormone on the body's tissues. These drugs are frequently used during this waiting period to control the symptoms, and they can usually be tapered off after six to twelve weeks, when the radioiodine-131 has corrected the hyperthyroidism. Occasionally, a patient may notice a tenderness over the thyroid gland several days after the treatment; this can be relieved by taking aspirin.

Patients should expect an improvement in their hyperthyroidism during the second month after treatment. Thyroid blood tests are usually checked every four to six weeks following therapy. By the end of the sixth month, a majority of patients will be cured of their hyperthyroidism; a second treatment with radioiodine is necessary in less than one-fifth of patients.

Once the patient is cured, he or she needs to be monitored for the development of hypothyroidism. At least 50% of patients treated with radioiodine-131 will develop hypothyroidism within one year following treatment, and most of the others will become hypothyroid in the future. It is important that patients be followed closely the first year, and have their blood tested annually after that. This allows the thyroid replacement to be started as soon as the thyroid function becomes underactive. Once hypothyroidism occurs, patients take a daily thyroid supplement for the rest of their lives.

## Follow-up after surgery

Radioiodine-131 is also used in treating thyroid cancer after surgery. If thyroid supplements are being taken, they are stopped to allow the secretion of Thyroid Stimulating Hormone (TSH) from the pituitary gland. This will

stimulate remaining thyroid tissue or cancerous tissue to take up the radioiodine-131 more actively, and will improve the effectiveness of the treatment.

Following radioiodine-131 administration, the thyroid hormone supplement is restarted. If the dose of radioiodine-131 exceeds 30 millicuries\* Federal Nuclear Regulatory Commission regulations require that the patient be hospitalized. This is not because the patient is at risk, but is done to ensure that the patient's radioactive urine is disposed of appropriately, and to avoid exposing others to higher levels of radiation in the patient's body. When the patient is discharged, usually after 48 to 72 hours, he or she should follow the same procedure as a patient who has been treated for Graves' disease.

## Benefits

It would be hard to underestimate the benefit radioiodine has had in diagnosing and treating patients with thyroid disease. More accurate diagnosis has led to better treatment and has helped avoid excessive surgery. Treatment of patients with Graves' disease has been made more comfortable, safer, and less expensive by using radioiodine-131 instead of surgery or long-term antithyroid medication. Radioiodine-131 has improved the follow-up and cure rate of thyroid cancer patients. Few medications have been so helpful and yet so safe.

\* A curie is a unit of radioactivity named after Madame Marie Curie, who discovered radioactivity. A typical dose of radioiodine-123 for thyroid scans is 100 microcuries (1/10,000th of a curie). A typical dose of radioiodine-131 for therapy for Graves' disease is 10 millicuries (1/100th of a curie). A typical dose of radioiodine-131 for therapy for thyroid cancer is 100 millicuries (1/10th of a curie).

*Dr. Baskin is the Director of the Florida Thyroid and Endocrine Clinic in Orlando. He is also the author of *How Your Thyroid Works*, a book for thyroid patients.*

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# Monthly Draw

Renew your Membership and become eligible for our Monthly Draw

Every month one lucky renewing member will receive a book on thyroid disease.

Our June 2001 winner was:  
**Mrs. Amelia Hodder**  
Mount Pearl, Newfoundland

Our July 2001 winner was:  
**Mr. Grant Davidson**  
Ottawa, Ontario

Our August 2001 winner was:  
**Mrs. Corinne Brown**  
Montreal, Quebec

Each of our winners received  
**"The Thyroid Gland  
A Book for Thyroid Patients"**  
by Joel I Hamburger, MD, FACP

## ESTATE PLANNING

Will You Do It Now?

If you have not made your will yet, will you do it now?

Will you remember the Thyroid Foundation of Canada?

If you plan to update your will, will you do it now? Will you help the Thyroid Foundation of Canada?

If we have helped you, will you help us help others? A bequest, an insurance policy, a tax exempt donation – will you think about it?

Will you do it now?

# Sources of information for thyroid cancer patients

## CancerConnection, Canadian Cancer Society

**Tel: Ontario, Newfoundland/  
Labrador: 1-800-263-6750**

**Tel: British Columbia/Yukon,  
Saskatchewan: 1-888-939-3333**

A telephone support program for thyroid cancer patients in British Columbia, Newfoundland/Labrador, Ontario, Saskatchewan and Yukon Territory.

CancerConnection is currently a core peer support program of the Canadian Cancer Society that provides emotional support to people diagnosed with cancer and their care givers. This telephone peer support is free, accessible, confidential and responsive.

CancerConnection was created in 1995, in Ontario, in response to the need for more accessible peer support programs and since then has grown to provide service in British Columbia and the Yukon, Saskatchewan, Newfoundland and Labrador. There are over 350 volunteers committed to providing the hope that comes from speaking with "someone who has been there".

All the volunteers have experienced cancer themselves, either through their own diagnosis or as a care giver and can truly understand.

In 1999 standardized training at the regional level was revised to support more volunteers coming through the CancerConnection program and expansion of service to include parents of children with cancer as a component of the care giver support. Targeted recruitment of volunteers with specific languages, cancer sites, age and types of treatment was conducted. **Cancer-Connection urgently needs volunteers.**



## Thyroid Foundation of Canada

PO Box 1919, Stn Main  
Kingston, ON K7L 5J7

**Tel: 1-800-267-8822**

**Fax: (613) 544-9731**

**Website: [www.thyroid.ca](http://www.thyroid.ca)**

The national office and your local chapter can provide a list of recommended books for reading. They can also provide an information article on a low iodine diet. Two members of the foundation, who have had thyroid cancer, are willing to be contacted by thyroid cancer patients.

Dianne Dodd:  
[dianne\\_dodd@pch.gc.ca](mailto:dianne_dodd@pch.gc.ca)

Kim McNally:  
[kosmo@kingston.net](mailto:kosmo@kingston.net)

(or call CancerConnection and ask to be referred to Kim.)

## ThyCa: Thyroid Cancer Survivors' Association, Inc.

PO Box 1545  
New York, NY 10159-1545 U.S.A.

**Tel: 1-877-588-7904**

**Fax: 1-503-905- 9725**

**Website: [www.thyca.org](http://www.thyca.org)**  
**E-mail: [thyca@thyca.org](mailto:thyca@thyca.org)**

This association was formed in 1995. Its three part mission is:

- To educate, so we and our families better understand our disease;
- To participate, so others learn from our experience;
- To communicate, so we and our healthcare professionals better understand each others needs.

Its goal is to ensure that no one has to be alone as they cope with the unique challenges of this disease. They accomplish this through many services, one of which is a recently formed e-mail support group for those coping with advanced thyroid cancer.

## The Head & Neck Cancer Foundation

2345 Yonge Street, Suite 700  
Toronto, ON M4P 2E5

**Tel: (416) 324-8178 ext 228**

**Fax: (416) 324-9021**

**Website:**  
[www.headandneck.ca](http://www.headandneck.ca)

A federally registered charity with the goals of raising money for research, support of physicians and public awareness. The charity has a medical sub-committee comprised of a revolving series of doctors, oncologists, hematologists and nuclear medicine specialists who review the grant applications and determine who receives funding. The website has thyroid cancer information.

## Dr. Daniel Drucker, Toronto General Hospital

**Website: [www.mythyroid.com](http://www.mythyroid.com)**

Dr. Drucker designed and maintains an extensive website of information on thyroid disease and treatment. The section on thyroid cancer treatment contains many topics including frequently asked questions and a section of news items describing current research findings and issues relating to the detection and treatment of thyroid disease.

## The Light of Life Foundation

**[www.lightoflifefoundation.org](http://www.lightoflifefoundation.org)**

A support group for thyroid cancer patients, founded in 1996 by Joan Shey at Sloan-Kettering Cancer Center, New York, NY, following thyroid cancer surgery. In addition to the emotional support she provides to thyroid cancer patients, Joan has also written a low iodine cookbook. Joan's commitment has extended to the support of research about thyroid cancer.

# The autoimmune diseases: *united they stand*

Two of the major diseases affecting the thyroid gland, Graves' disease and Hashimoto's (chronic lymphocytic) thyroiditis, are prime instances of autoimmune diseases. They represent, in fact, two of the most common examples of a group of some eighty autoimmune diseases. This brief article describes some of the common characteristics shared by the autoimmune diseases; it also suggests reasons why it is important that they be considered as a group as well as separately.

## Autoimmune disease defined

The basic definition of an autoimmune disease is a disorder caused by an autoimmune response; i.e., an immune response directed to something in the body of the patient. Since autoimmunity can affect any organ in the body (including brain, skin, kidney, lungs, liver, heart, and, of course, thyroid), the clinical expression of the disease depends on the site affected. In our system of highly compartmentalized medicine, patients with autoimmune disease may be cared for by physicians in virtually any medical specialty.

For many years, the medical establishment was skeptical of the existence of autoimmunity, since it seemed to defy common sense. Why would a person develop an immune response to himself, rather than to an invading germ? When we realize that the immune response is a powerful and complex biological reaction, however, we can understand that, on occasion, the reaction can misfire. These misfirings of the immune system are the reason that autoimmune diseases occur. Sometimes autoimmunity can be the initiating cause of the disease and, in other cases, autoimmunity can contribute to, or exaggerate, a disease caused by something else. The presence of an autoimmune response is signaled by the appearance of autoantibody in the circulation, and so the demonstration of a particular autoantibody usually constitutes the path to recognize an autoimmune disease.

## Multiple causes: genetic

What could cause the immune system to misfire in such a harmful manner? Part of the answer is genetic. All of the

by  
**Noel R. Rose, MD, Ph.D.**

autoimmune diseases show evidence of a genetic predisposition. No single gene by itself causes an autoimmune disease; instead, a coalescence of several genes in certain individuals, in the aggregate, heightens significantly the overall possibility of developing an autoimmune disease. Some of these genes may be specific for a certain disease, but others predispose to autoimmunity in general. That explains why a single patient may have more than one autoimmune disease or why autoimmune diseases are more common in some families than others.

For the patient, this is an important bit of information, because it means that she must alert a physician to the presence of autoimmune disease in the family. We use the pronoun 'she' because most autoimmune diseases occur more frequently in women. The reason for this sex-related difference is not known, but it probably reflects the involvement of hormones in regulation of the immune response.

## Multiple causes: environmental triggers

Another common characteristic of all of the autoimmune diseases in humans is that an outside agent is required to initiate the harmful autoimmune process. These agents are called environmental triggers. Even with a genetic predisposition, most people do not develop an autoimmune disease unless something external acts on their body. Sometimes, this may be infection: for example, a well-known autoimmune disease, rheumatic fever, is associated with a preceding infection by a streptococcus.

Another autoimmune disease, lupus, may be precipitated by exposure to a particular drug or sunlight. Sometimes, components of the diet may influence the development of disease; for example, in autoimmune diseases of the thyroid, dietary iodine may be an important initiating factor. It must be emphasized, however, that these environmental triggers act only in individuals with a genetic predisposition and not in the

population at large. If the environmental agent can be identified and the patient warned to avoid it, the autoimmune disease may never occur, even in the most highly disposed individual. The important outcome of the human genome project will be the identification of genes that contribute to an unusual autoimmune susceptibility. Individuals with the greatest risk can then be forewarned.

## Overlapping diseases

Thus, it is important, from the clinical point of view, to consider the autoimmune diseases as a united group of disorders. The presence of one autoimmune disease will alert the physician and the patient to the possibility that a second or third autoimmune disease may occur in the same individual or in other members of the same family. The presence of one autoimmune disease may be a sign of heightened susceptibility to a second disease.

## Research for new treatments

A great deal of benefit also arises from considering the autoimmune diseases together in the realm of medical research. Virtually all autoimmune diseases are dependent upon the production of an abnormal population of T cells, one of the circulating white blood cells. An effective treatment of autoimmune disease, more efficacious than anything we have in our armamentarium, would come from finding ways of identifying and turning off these disease-producing T cells. As modern molecular immunology has taught us, the T cell has a unique surface structure. By use of experimental animals, we are learning to identify these disease-associated structures on T cells and to develop methods to eliminate them.

The fundamental level of research cuts across all of the autoimmune diseases. The productive interaction among investigators who study the particular spectrum of the autoimmune diseases, such as the thyroid diseases, multiple sclerosis, lupus, rheumatoid arthritis, the inflammatory bowel diseases, and many more, will teach us the basic lessons necessary to devise more effective, long-term treatments for the broad range of autoimmune disease.

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## A major problem requires a major response

In the last analysis, the most important reason we should begin to view the autoimmune diseases as a unified group is to give them greater visibility. Most autoimmune diseases are relatively rare and most are not fatal. Therefore, they never appear on the public 'radar screen' as a serious health problem requiring more attention and more funding. Taken together, however, the autoimmune diseases occupy the third or fourth place in the list of prevalent diseases in our country.

The majority require lifetime care and treatment, which is an expensive budget item for both the individual and the country. Moreover, an autoimmune

disease is debilitating for the patient, and often destructive of a productive life style of an entire family.

It is time, then, that we start to think of autoimmune diseases as a unified group and to gather our forces on the battleground for a major investigative attack on the fundamental problem.

*Dr. Noel R. Rose is Professor of Pathology at Johns Hopkins School of Medicine and Professor of Molecular Microbiology and Public Health at Johns Hopkins University School of Hygiene and Public Health. In addition he is the Director of The Johns Hopkins Autoimmune Disease Center. He serves a chairman of the Scientific Advisory Board of the American Autoimmune-Related Disease Association.*

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*thyrobulletin* is published four times a year: the first week of May (Spring), August (Summer), November (Autumn) and February (Winter).

Deadline for contributions are:

March 15, 2002 (Spring)

June 15, 2002 (Summer)

September 15, 2002 (Autumn)

**December 15, 2001 (Winter)**

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# Membership/Donation Form

## Awareness ♥ Support ♥ Research

New memberships run for one or two years from the receipt of this membership application.

All members receive *thyrobulletin*, the Foundation's quarterly publication.

**Yes!**

I will support the  
Thyroid Foundation  
of Canada!

Membership Level	One Year	Two Year
<input type="checkbox"/> Regular	\$20.00	\$35.00
<input type="checkbox"/> Senior 65+	\$15.00	\$25.00
<input type="checkbox"/> Student	\$15.00	\$25.00
<input type="checkbox"/> Family	\$25.00	\$45.00

### Donations (Circle Your Choice)

Education & Services, Chapter Programs, National Research, Where Need is Greatest \$ \_\_\_\_\_

**Total:** \$ \_\_\_\_\_

I will be paying my membership/donation by:

Personal Cheque (enclosed and payable to Thyroid Foundation of Canada) or,

Visa or  MC #: \_\_\_\_\_ Expiry Date: \_\_\_\_\_

Signature: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ Province: \_\_\_\_\_ Postal Code: \_\_\_\_\_

Tel: \_\_\_\_\_ Fax: \_\_\_\_\_ E-mail: \_\_\_\_\_

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We accept your membership fees and/or donations by mail or fax.

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**THYROID FOUNDATION OF CANADA, PO Box/CP 1919 Stn Main, Kingston ON K7L 5J7**

Tel: (613) 544-8364 or (800) 267-8822 • Fax: (613) 544-9731 • Website: [www.thyroid.ca](http://www.thyroid.ca)

**Please Continue Your Support—We Need You!**

# National Office/Bureau national

**Staff/équipe** **Katherine Keen**, National Office Coordinator/Coordinatrice du bureau national  
**Helen Smith**, Membership Services Coordinator/Coordinatrice des services aux membres

**Office Hours/** Tues.- Fri., 9:00 am - 12:00 pm/1:00 pm - 4:30 pm  
**Heures du bureau** Mardi à vendredi, 9h00 à 12h00/13h00 à 16h30

**Tel:** (613) 544-8364 / (800) 267-8822 • **Fax:** (613) 544-9731 • **Website:** [www.thyroid.ca](http://www.thyroid.ca)

## Chapter & Area Contacts/Liaisons pour les sections et districts

### BRITISH COLUMBIA/COLOMBIE-BRITANNIQUE

Cowichan	(250) 246-4021
Vancouver	(604) 266-0700
Victoria*	(250) 592-1848

### NOVA SCOTIA/NOUVELLE ÉCOSSE

Halifax	(902) 477-6606
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### PRINCE EDWARD ISLAND/ÎLE-DU-PRINCE ÉDOUARD

Charlottetown	(902) 566-1259
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### ALBERTA

Calgary	(403) 246-2841
Edmonton	(780) 476-3787

### NEWFOUNDLAND/TERRE NEUVE

Avalon/ St. John's	(709) 368-5068
Gander	(709) 256-3073
Marysville	(709) 279-2499

### SASKATCHEWAN

Saskatoon	(306) 382-1492
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### MANITOBA

Winnipeg	(204) 489-8749
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### ONTARIO

Burlington/Hamilton	(905) 637-8387
Kingston	(613) 389-3691
Kitchener/Waterloo	(519) 884-6423
London	(519) 649-5478
Ottawa	(613) 729-9089
Petawawa/Pembroke	(613) 732-1416
Sudbury	(705) 983-2982
Thunder Bay	(807) 625-1419
Toronto	(416) 398-6184

### QUEBEC/QUÉBEC

Montréal	(514) 482-5266
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### NEW BRUNSWICK/NOUVEAU BRUNSWICK

Moncton	(506) 855-7462
Saint John	(506) 633-5920

\* Area Contact/Contact régionaux

**Thyroid Foundation of Canada**  
**La Fondation canadienne de la Thyroïde**  
**PO BOX/CP 1919 STN MAIN**  
**KINGSTON ON K7L 5J7**



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