



Thyroid Foundation of Canada

thyrobulletin

La Fondation canadienne de la Thyroïde

Volume 25, No. 1

Spring 2004

Thyroid Alliance created

The physicians and staff at The Thyroid Foundation of America (TFA) have been concerned for some time about organizations and individuals presenting information that is not backed by thyroid research, with advice that could be misleading in the least, and dangerous and even life-threatening at the extreme.

In addition, there are a number of books that have been specifically written for patients, most with very good intentions and containing information designed to help patients understand and deal with thyroid problems. We at TFA have long felt that there should be some effort to identify these medically accurate Websites, organizations, books, and other literature, and about five years ago proposed the idea of creating a Thyroid Alliance. The concept was simply to identify organizations whose entire focus was on medically accurate information, groups that would avoid hearsay and hype. We preferred to focus on the organizations that we felt were doing the right thing and not speak negatively about other organizations and literature that had some benefit and willingness to bring before patients the views that might not be in the medical mainstream.

The American Thyroid Association (ATA) is a group of about 700 thyroid specialists who do research, share ideas at national meetings, and offer information to patients as well as physicians on their excellent Website www.thyroid.org. Two years ago the ATA began talks with five patient groups in North America that they identified as providing accurate medical information about the thyroid to patients and the general public. These groups included the Thyroid Cancer Survivors' Association (ThyCa), the National Graves' Disease Foundation, The Light of Life Foundation for patients with thyroid cancer, the Thyroid Foundation of Canada and The Thyroid Foundation of America.

All groups have been very positive in their support of the idea of an alliance, and I am pleased to say that at this year's annual meeting of the ATA in September 2003, all those represented agreed with the creation of a formal Alliance. Canada was unable to be present.

We had the added benefit this year of representation from the Thyroid Federation International (TFI) by Yvonne Anderson, who is the president of the Western Swedish Thyroid Association. Yvonne

participated in these discussions and was going to present the results of the meeting to TFI at its annual meeting in Edinburgh, Scotland, later in 2003. Once the ATA has an option to review the programs of these international groups, I hope that some or all may have the opportunity to become a part of this important alliance.

There is a tremendous advantage when patient organizations work closely with physician groups to help assure the credibility, accuracy, and timeliness that patients need in order to keep up with their thyroid problems. They want to know when a new treatment or test for thyroid cancer is developed, for instance, whether it is medically sound and safe. We hope that these closer ties will also make patients more interested in helping to raise funds for thyroid research that can help us all.

Thanks to the ATA and all the participants of the conference for giving us hope for a new Thyroid Alliance in the very near future.

Lawrence C. Wood, MD, FACP, President, The Thyroid Foundation of America.

Reprinted from The Bridge, publication of TFA.

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Good-bye and thank you



Margaret Burdsall, Volunteer



Rick Choma, Volunteer



Nathalie Gifford, Volunteer



Mary Salsbury, Volunteer

For varying personal reasons we, the above four Kingston members of the *thyrobulletin* team, feel the time has come for us to retire from our volunteer positions and hand our responsibilities over to others. We have enjoyed the experience, the challenge and the hours of hard work. We hope that you, our readers, benefit from the information in *thyrobulletin*.

Robert Mactavish, a former editor, aimed to make each issue better than the previous one – and this is an ideal we have tried to follow.

The success of *thyrobulletin* is due to the cooperation of doctors, organizations, authors and members who all contribute to the content, and to the support of our sponsors, comments from our readers, the excellent teamwork of volunteer committee members and the co-operation of our

desktop publisher, printer, mail distributor and national office staff. Warm thanks to all on whose help and support we have come to depend over the years.

We extend, also, best wishes to those who will follow us as members of *thyrobulletin's* editorial team.

Volunteer members thyrobulletin editorial team, Rick Choma, Editor, Margaret Burdsall, Nathalie Gifford and Mary Salsbury

From the national office

Thank you

Many thanks to Barb and Ron Manor for their financial support of the Foundation through the sale of Nevada tickets at Gateway Newsstand, Kingston Shopping Centre. In the past two years, in excess of \$26,000 has been received by the National Education & Services Fund as a result of this partnership.

Stamps

Eileen Davidson, long-time volunteer in the national office (see *thyrobulletin* Vol. 23, No. 2, Summer 2002) is still an avid stamp collector. Eileen shares her stamps with members of the Kingston stamp club, which in turn packages surplus stamps for sale to children at stamp shows, to encourage children to become stamp collectors.

All the stamps on correspondence to the national office are shared between Eileen and Helen Smith, national membership services coordinator. Helen uses the stamps for crafts for her 25-member Girl Guide group. They welcome all donations of stamps. Please send to: Eileen Davidson, Thyroid Foundation of Canada, PO Box 1919 Stn Main, Kingston ON K7L 5J7.

Remember!

June
is Thyroid Month

*Please support the
Thyroid Foundation.*

*We appreciate your
financial assistance.*

Thyrogen™

Status of provincial cost coverage

British Columbia – Full cost coverage is approved under the B.C. Cancer Agency.

Alberta – The Alberta drug plan has determined that coverage is the responsibility of individual hospitals or the Cancer Agency.

Saskatchewan – Full cost coverage under the Provincial Cancer Agency. Radiation oncologists make a special access request to the cancer centre.

Manitoba – Full cost coverage is approved under Manitoba Cancer Care. Request must be made by a specialist.

Ontario – Thyrogen is covered under the Ontario Drug Benefits Program - limited use. Limited use means doctors need to write a prescription for patients that meet the criterion (for the use in the monitoring of patients with well-differentiated thyroid cancer) on the government supplied limited use prescription pad and note the code number 368.

Quebec – The Quebec drug plan has determined that coverage is the responsibility of individual hospitals. Thyrogen is listed in the formulary for hospitals or health institutions. The listing comes with a criterion that it is for patients who are intolerant to withdrawal or where withdrawal is contraindicated.

Newfoundland – Full cost coverage through hospitals

Nova Scotia, New Brunswick, Prince Edward Island (Atlantic Committee) – Atlantic Common Drug Review Process has recommended full coverage. Individual provinces will consider patient specific requests.

Territories – Fully covered on request

First Nations – Fully covered as an NIHB benefit

Other federal programs:
Department of National Defence, Veterans Affairs Canada, Corrections Canada, RCMP – Fully covered benefit

Monthly Draw

Every month one renewing member receives a book on thyroid disease. Renew your membership now and become eligible for our monthly draw.

December 2003 winner

Ms. Janet Leffek
Victoria, British Columbia
received a copy of
*"Thyroid Problems;
a guide for patients"*
by Ivy Fettes, PhD, MD, FRCPC

January 2004 winner

Mrs. Angela Silver
Montreal, Quebec
received a copy of
*"Thyroid Problems;
a guide for patients"*
by Ivy Fettes, PhD, MD, FRCPC

February 2004 winner

Mrs. Bev Mazar
Calgary, Alberta
received a copy of
"How your Thyroid Works"
by Dr. H. J. Baskin

Thyrogen™

Patient reimbursement helpline

1-866-401-8323

A reimbursement HELPLINE has been set up to help you get coverage for Thyrogen under your insurance plan. If you have questions about your coverage, you can call the Thyrogen Reimbursement HELPLINE. Reimbursement specialists will be able to help you verify your benefits and answer any other questions you may have about Thyrogen reimbursement.

Most private insurance companies cover Thyrogen. You should note that not all insurers and plans reimburse the same way however. For example, some private plans provide unrestricted open coverage where you need only fill your prescription at your local pharmacy. For others,

you or your doctor may need to file additional documentation to obtain a prior authorization for reimbursement of Thyrogen costs. You should also note that Thyrogen is being treated as a drug by most insurers while some are managing coverage under the diagnostic services section of the major medical or supplementary health insurance plan.

The Thyrogen Reimbursement HELPLINE is open from 8:00 am until 8:00 pm EST, Monday through Friday. Simply call 1-866-401-8323 and a specialist will be pleased to help you.

Above articles reprinted with permission from genzyme Canada Inc. For more information: www.genzyme.ca.

NOTICE TO MEMBERS

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

Please use the **Membership/Donation Form** on page 19 or our secure payment system at:
www.thyroid.ca/english/membership.html.

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.

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

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

Founded in/Fondée à Kingston, Ontario, in 1980

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

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Legal Adviser – *Cunningham, Swan, Carty, Little & Bonham LLP*

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

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

La Fondation canadienne de la Thyroïde est un organisme de
bienfaisance enregistré numéro 11926 4422 RR0001.



Thyroid Foundation of Canada

thyrobuletin

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Important Notice:

The information contained within is for general information only and consequently cannot be considered as medical advice to any person.

For individual treatment or diagnosis consult your health care professional.

Avis Important:

Les renseignements contenus à l'intérieur sont à titre d'information générale et conséquemment personne ne doit les considérer comme conseils médicaux. Pour traitement ou diagnostic individuel veuillez consulter votre médecin.



Bozica Popovic,
B.Sc.Pharm, Manager
DRUGStore
Pharmacy at
Loblaws, Kingston
Centre

Ask a pharmacist

I am frequently asked the following question. I have to take calcium supplements on a daily basis for my bones. I've heard it can interfere with my thyroid hormone therapy. Is that true and what should I do?

Yes, it is true that calcium (Ca) has a potential to affect intestinal absorption of levothyroxine (Eltroxin, Synthroid) as well as some other drugs and minerals.

A recent study, conducted by N. Singh et al¹ at the Veterans Affairs Greater Los Angeles Healthcare System, Los Angeles California, and sent to the Foundation by Merrill Edmonds, MD, FRCPC, St. Joseph's Health Centre, London, Ontario, showed that levothyroxine blood levels can be reduced up to 40% if the hormone is taken together or immediately after calcium supplement. The study has also shown that this effect of calcium on levothyroxine, although decreasing with time, can actually last for quite a long period. In that particular study calcium carbonate (CaCO₃) was used but one can

assume that other forms of calcium or food rich in calcium (milk, cheese, yogurt) would have a similar effect.

The reason for this lies in the chemical nature of calcium, and regardless of the source it has the ability to bind (trap) levothyroxine in the bowel. As a result much smaller amounts of thyroid hormone get absorbed into the blood stream and delivered to the body cells. Consequently people on thyroid hormone therapy feel as if they are not getting enough medication and might experience hypothyroid symptoms.

Based on these facts we have to see how a person who has to take 1500 mg of calcium per day can actually do it, and as much as possible avoid unwanted calcium/hormone interaction.

We know that the thyroid hormone should be taken with water only, first thing in the morning as soon as we get up. All our morning routine and activities should come after that. In this way we follow the natural rhythm of the thyroid gland. The gland is most active in the early morning, preparing the body for daily physical and mental activities, and less active in the evening or night when we mostly rest.

For many people with no severe digestive problems ½ hour would be sufficient time between their thyroid hormone and

breakfast, coffee, etc. At that time excess milk or calcium supplements should be avoided. One can start calcium supplements around two hours after taking the hormone. Because doses of calcium greater than 500-650 mg can't be absorbed they should be divided and taken two or three times a day, depending on how much one needs

To prepare a relatively calcium-free stomach and intestines for the next thyroid pill (next morning) the last dose of calcium in the day has to be taken at least eight hours before the thyroid pill of the next day. Taken separately in this way will reduce the possible interaction to the minimum and one gets the benefit from both worlds. Additional recommendations on how to take calcium supplements would be to take it with water or juice. Don't take it with milk because that can precipitate Milk-alkali Syndrome - an unpleasant condition involving a lot of flatulence and diarrhea.

Bozica Popovic, pharmacist, is the facilitator of the every 4th Sunday of the month informal thyroid discussion at Loblaws, Kingston Centre, Kingston, Ontario.

¹ Singh N, Weisler SL, Hershman JM, Thyroid 2001, October 11 (10) 967-71, Department of Endocrinology and Metabolism, Veterans Affairs Greater Los Angeles Healthcare System, California 90073, U.S.A. Nalini.Singh@med.va.gov



- Awareness
- Support
- Research

ESTATE PLANNING

If you plan to update your will, will you do it now?

If the Thyroid Foundation of Canada has 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?



Robert Volpé, OC, MD, FRCPC, MACP, Medical Adviser to the Foundation

Letters to the doctor

I am writing you at this time after reading the Foundation's brochure *Thyroid Cancer*. In February 2002 I had a total thyroidectomy here in Moose Jaw and a lymph node removed as well. I had the regular follow-up with radioactive iodine treatment within two months and a check-up at the Alan Blair cancer clinic in Regina.

One year later I had another radioiodine test. I never did hear the results so I assume it was negative. I was again to have a follow-up at the Alan Blair clinic. The doctor changed my appointment five times and I finally got fed up and did not go back. As I am 60 and mobility handicapped, my wife had to book off work each time to take me to Regina (40 km). Besides the inconvenience of cancelled appointments, there was an income loss. The doctor cancelled these appointments for his own convenience. I did write the doctor asking if there was any chance of my cancer recurring and asked him to correspond with me. I never heard back from him. I guess he has enough patients without me.

My question to you is: should I go cap in hand and try to re-book? Is there a chance of my thyroid cancer coming back in some form? I would appreciate hearing from you at your earliest convenience.

Robert Bushnell, Moose Jaw SK

Follow-up is very important after treatment for thyroid cancer. You should really make arrangements to be seen again. While the chance of recurrence is remote, one cannot be certain about this without follow-up. If your serum thyroglobulin levels are undetectably low this would be a good prognostic sign.

Recently when looking for information on the Web one subject appeared which was a "soy alert". I was most surprised to read about all the negative comments concerning soy products and how harmful they can be to anyone's health and, in particular, to those on thyroid medication. I now know what has been causing havoc to my system this past year and a half since I had been taking soy milk on a daily basis and tofu occasionally. My thyroid medication has had to be consistently lowered because of heart palpitations – for which I was consequently sent for various heart tests. The test results were okay. The only explanation to what was happening to me was that my hormones were acting up! I have also recently discovered that I have multi-nodules on my thyroid gland. I truly believe the soy products caused the medical problems that occurred because the only changes in my life in the past year and a half have been the addition of soy milk and tofu to my diet.

I would like to know what negative effects soy milk has for people with hypothyroidism and I would like to ask the Foundation why there is no information being placed in *thyrobulletin* on such important issues as:

- when is it best to take thyroid medication?
- what foods should one avoid completely?
- what is the waiting period before taking certain foods after having taken thyroid medication?

Cecile Emond, Gatineau, QC

Thank you for your e-mail regarding the effects of soy on thyroid hormone medications. As for the changes in your thyroid function, as indicated in your letter, you should consult with your own family physician or your endocrinologist who can carry out various tests to determine the cause of these problems.

*Soy products do slightly reduce the absorption of thyroid hormone, and may possibly require an increase in dosage. In the past, the Thyroid Foundation has printed articles in *thyrobulletin*: volume 24- 1 Spring 2003 (Complementary and alternative medical therapies for thyroid disorders); volume 23-4 Winter 2003 (Levothyroxine therapy); volume 22-1 Spring 2001 (Drug interactions in thy-*

roid disease); volume 20-1 Spring 1999 (Thyroid hormone drug interactions).

To achieve optimal absorption, thyroid hormone medication should be taken with water on an empty stomach first thing upon arising, at least one half hour before any food. However, if it is taken with food, there is only a modest reduction in the absorption of thyroxine. There are no particular foods that have to be avoided although moderation is advisable. Various medications have possibly different effects on the absorption of Thyroxine, which is usually minimal in severity, although calcium and iron therapy can cause quite marked reduction in absorption of Thyroxine. It would be advisable to discuss this problem with your pharmacist before taking such treatments.

HEAD&NECK
CANCER FOUNDATION

Thyroid Foundation of Canada gratefully acknowledges the support of the Head & Neck Cancer Foundation in sponsoring *Letters to the doctor*.

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June 15, 2004 (Summer)
 September 15, 2004 (Autumn)
 December 15, 2004 (Winter)
 March 15, 2005 (Spring)

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 Kingston, ON K7L 5J7

Fax: (613) 544-9731
 E-mail: thyrobulletin@on.aibn.com

“Shakin and bakin” from just a “little” cancer

In lay terms, the disease of hypoparathyroidism (HPTH) is one where the parathyroid glands are not functioning properly or at all. These glands are extremely small, and are usually next to the thyroid gland. From my unique point of view, they are more important than the thyroid because they cannot be ‘replaced’, as can the thyroid gland function, with synthetic thyroid hormone (Synthroid or Eltroxin).

I have surgical onset hypoparathyroidism following a total thyroidectomy for thyroid cancer in 2001. Simply put, the parathyroid glands produce parathyroid hormone (PTH) which directs and controls calcium levels in our bodies, somewhat like a sophisticated computer program, giving more calcium to areas that need it and removing calcium from areas that have too much. Much more than just a daily supplement, calcium is essential to our survival. The calcium in our bodies acts as a buffer or barrier between our brain and muscles.

Low calcium (hypocalcemia) means a thinner barrier and so muscles are constantly bombarded by brain signals creating twitches, jerks, spasms, contractions, etc. These manifestations are called tetany. Extreme low-calcium situations are lethal. Remember, the heart is a muscle! Just think how many muscles make up your body . . . and imagine for a moment having a ‘calcium computer’ breakdown.

My story

Because I had no history of thyroid disease before my cancer diagnosis, I knew only vaguely what a thyroid gland was and that it was in the neck. My only symptom had been burping, for no reason. My former husband had been annoyed when I had non-stop burping at bedtime or during the day. He insisted I did it on purpose.

Any other symptoms in the years prior to my diagnosis I attributed to celiac disease, a malabsorption syndrome that manifests in many ways.

Diagnosis

It was in Ottawa in October 2001 that my very excellent GP first noticed my ‘burp spot’ (as I affectionately called it) during a regular physical. She asked me what this was. I said, “If you press there, I may burp for 15 minutes or half a day”. Being thorough she obliged, unfortu-



by
Anne-Marie Smith

nately I’d had curry that day. She insisted on a follow-up with an Ear, Nose & Throat (ENT) specialist. His exam of my throat revealed no abnormalities and I was sent for an ultrasound of the neck. The ultrasound technician was concerned and summoned the radiologist who turned out to be someone I knew. The conversation that ensued was honest and revealing. I might have thyroid cancer. What he described as a ‘mass’ would need a biopsy and most likely surgery. I was totally proactive and gung-ho to have this biopsy

The thyroidectomy was done on February 5th 2001 . . . Since then I have been a ‘frequent flyer’ in emergency with tetany on the average twice a month.

and get rid of this cancer! I developed infection after the biopsy. In my case, I should have taken this as the first sign of Murphy’s Law.

When the results came in, my ENT specialist told me I had a ‘little cancer’ and scheduled surgery for a date four months away. He confidently assured me I would be home in one sleepover and that of all cancers, this was the best cancer to have.

At my pre-op appointment, some mention was made of even smaller glands that were attached to the thyroid, parathyroid glands. I was told to report any symptoms

of facial tingling or mouth numbness since this would mean I would need to take some calcium for a few days to help those glands – an easily remediable situation.

The thyroidectomy was done on February 5th 2001 and within 24 hours I experienced tetany. I awoke suddenly from a deep sleep because I couldn’t breathe and I became aware that my face was moving, all on it’s own, like waves were rippling between the skin and muscles. It’s impossible to describe something you’ve never experienced before but I did try! I rang the nurse who assured me I was just having some sort of post-traumatic effect from a difficult surgery, just anxiety. I was comforted and returned to LaLa Land with morphine.

The next morning I awoke to totally cramped hands. They were locked in a peculiar position. At lunchtime, one of my first solid meals was waiting to be eaten and I was desperate to return to normal. I somehow held a fork and got busy. I assumed the difficulty I had swallowing was because of the thyroid surgery. Later, I fell asleep with the funny hands, my nurse was watching.

The surgeon popped in and said my calcium was low. He had previously told me my parathyroid glands had indeed been preserved so I assumed this was a standard outcome and a temporary situation.

What followed was an entire week of attempting to stabilize my calcium. I was on calcium, intravenous (IV) and oral, 24 hours a day and was poked several times a day and even at night to test levels. (Forget about sleeping in hospital!) My all-time low was 0.9 ionized calcium.

This was only the beginning. Since February 2001, I have been a ‘frequent flyer’ in emergency with tetany on the average twice a month. Technically, low-calcium situations can happen with ‘hyperventilation’ since this lowers ionized calcium in the blood. With no parathyroid hormone to correct the low level, hypoparathyroid patients go into tetany. Hyperventilation can occur in several mundane ways . . . having a good laugh, watching a horror movie, being too tired, too hot, too cold, in pain, nervous, etc. It takes only a slight change in breathing pattern for a hypoparathyroid patient to start feeling ‘out of body’ . . . not in control of those muscles.

continued on page 9

Foundation's mailbox

I really appreciate the information from Mrs. Burdsall, president Kingston area chapter. I was hoping to go to the meeting at Loblaws in November. However, the bus I was waiting for did not arrive.

Thank goodness for your group since I have not found that my family doctor is willing to discuss thyroid problems with me beyond telling me my TSH is very low. Again, thank you for the thyroid information package. It gives one hope that with the right treatment one can feel better.

Joan Heyland, Kingston ON

We were saddened to hear of the untimely passing of Jack Tarantello. I had a brief affiliation with Jack at the national office and my husband worked with him at Elbertsen Windows and Doors in Gananoque, near Kingston ON.

In his memory we would like to make a donation of \$100 to the Thyroid Foundation of Canada to be used for Kingston chapter work. I know his services and friendship will be missed by my mother, Margaret Burdsall, and by her friend and co-worker, Nathalie Gifford, as well as many others in the Kingston area.

Jane and Maurice Pinco & Family
Calgary, AB

The members of thyrobulletin editorial committee are deeply gratified to have received so many expressions of thanks from family members, colleagues and friends, for the tribute to Jack Tarantello in the previous issue.



We need you

- ✓ consider a gift membership
- ✓ renew your membership
- ✓ consider a donation
- ✓ ask a friend to join

Visit our website at www.thyroid.ca/english/membership.html if you wish to use a credit card on our secure payment system.

Remember . . .
the only gift too small is
no gift at all!

Thank you for your past support.
Your help is needed more than ever.

Shakin and bakin . . . continued from page 8

Vague symptoms come and go on a daily basis but when severe tetany starts (usually with locked hands and a Popeye jaw) I have a 20-30 minute window of opportunity to get to a hospital before my hypoparathyroid 'bodysuit' of spasms zips shut!

Once I'm in tetany here are, in my own words, the symptoms I experience.

- Warning 'tingling' actually feels more like stinging – usually in face.
- Getting 'very quiet' – tired . . . If I'm sitting at the time, I might only notice I'm in spasm if I try to speak or walk.
- The 'sinking' or queasy feeling and sensation of loss of physical control . . . like 'going under' from anaesthesia – a sense of lightness.
- Laryngeal spasms – affect speech, swallowing, breathing.
- Hand and foot spasms – thumb locks inside hand, feet stiff.
- Leg stiffness or shakiness.
- Involuntary tears/urinary incontinence.
- Eye muscle spasms/contraction – fixed stare or squint.
- Facial spasms:
 - 'Popeye mouth' – 'roving spasms' of jaw, mouth, lips and tongue;
 - 'monkey nose' – numbness of nose and mouth area.

- Neck spasm – tightening or torquing unable to support head (need to lie down).
- Torso (thoracic) – depending on body position.
- Chest pains (despite being told the heart is 'normal').
- Movements that are wide in amplitude – that totally 'overshoot'.

The path to wellness – education

Well, it's been over three years since my surgery, and along the way, I have realized that no one knows much about this disease called hypoparathyroidism. I am a teacher and I found that researching and reading about HPTH gave me some sense of control. The learning curve was huge!! However, knowing what was happening, being able to name it, made it much less scary.

It is important to be able to communicate clearly about this condition with health professionals, from the admissions' clerk to nurses and doctors, nuclear medicine, the pharmacy and labs and to be able to understand test results and procedures.

Today – how I cope: Laughing in the face of danger!

I am a visual artist and musician and teacher with post-graduate education. Over the years, I've worked in a variety of professions including teaching, filmmaking, competitive rowing, performing

musician (lyric soprano – before the thyroidectomy of course!). I know my body well, possess a strong sense of self and have an extremely good sense of humour. These gifts have helped me through the HPTH labyrinth.

Though laughing has sometimes actually brought on tetany, in general, humour helps – letting emergency staff know you only look silly but that you're still alive 'in there'.

Attitude: I find it's important to remain 'light' during tetany: not fighting the spasms, going with them because it hurts less (jaw especially), breathing 'simply'. I cannot relax my body because that is simply out of my control. I can only control my thoughts.

Many heartfelt thanks to James Sanders and his marvellous website (www.hypoparathyroidism.org) without which I would have lost heart and not had the courage to get the care I need.

For more information, visit www.hypoparathyroidism.org and especially see the articles section which contains treatment protocols and diet information.

Anne-Marie Smith, a member of Ottawa chapter, wrote this article for presentation as part of an Ottawa chapter Patient Forum education meeting. She thanks the Ottawa chapter for allowing her to present her story and Dianne Dodd who offered to read it.

Chapter coming events

Free admission – everyone welcome

Burlington/Hamilton

Location: Marquis Gardens Banquet Centre, Hamilton, 1050 Rymal Road East (near Upper Ottawa Street). Free parking. In partnership with St. Joseph's Healthcare, Healthstyles/Spring Series 2004.

- Wednesday June 2, 2004 7:00 pm - 9:00 pm. Speaker: **Dr. William Harper**, endocrinologist Hamilton Health Sciences Centre. Topic: *Hypothyroidism*. Blood tests – what they measure, T3/T4 combination therapy – what the studies show. The long-term effect of hypothyroidism on the body. Thyrogen use for thyroid cancer patients. No registration necessary.

Location: 707 Galaxy Banquet Hall, Oakville. In partnership with Halton HealthCare

- October 2004 (to be confirmed) 6:30 for displays and refreshments. Speaker **Dr. Nageen Hameed**, endocrinologist. Topic: *Hypothyroidism*.

Location: Burlington Art Centre, Shoreline Room, 1333 Lakeshore Road, Burlington

- Tuesday November 9, 2004, 7:00 pm Speaker TBA. Topic: *Thyroid disease and the family*.

Location: 33 Alterra Blvd, Ancaster

- 4th Annual Spring Flower Sale Saturday May 29 and Sunday May 30, 8:00 am to 3:00 pm. Shop early as last year was a sell-out.

For information on these events call toll free: 1-866-377-4447 or 905-381-0475.

Kingston

Location: Ongwanada Resource Centre, 191 Portsmouth Avenue, Kingston

- Tuesday May 18, 2004, 7:30 pm. Speaker: **Dr. R.W. Hudson**, endocrinologist, Professor & Chair Division of Endocrinology, Queen's University. Topic: *Thyroid cancer – is there ever a cure?*

Location: Christ Church Parish Centre, 990 Sydenham Road, Kingston

- Saturday, May 22, 2004. 10:00 am - 2:00 pm **Health & Wellness Fair**. There will be displays and presenta-

tions from health care organizations and support groups to showcase services offered in Kingston. No charge. Visit the thyroid information table.

For information call: 613-545-2327.

Location: Loblaws Upstairs, Kingston Centre, Princess Street at Sir John A.

- Fourth Sunday each month, 3-4 pm. Spring season of informal thyroid information sessions. Bo Popovic, pharmacist and a representative from Kingston chapter will be present.

For information call: 613-530-3414.

Kitchener/Waterloo

Location: Kitchener Public Library, lower level. 85 Queen Street North, Kitchener. Wheelchair accessible.

- Wednesday April 28, 2004, 7:00 pm. **Dr. Terri Paul**, Assistant professor, Endocrinology & Metabolism, St. Joseph's Health Centre, London. Topic: *Obesity: what you and your thyroid can do*.

For information call: 519- 884-6423.

London

Location: Central Library, Galleria, 251 Dundas Street, London. Two hours free parking for library patrons.

- Tuesday, May 18, 2004. 7:30 pm. **Sheila Grose**, Dietitian, St. Joseph's Health Centre. Topic: *Food for thought!* New nutrition labelling guidelines, cholesterol and fat information in relation to weight control,, healthy food choices and concerns re pre-diabetic diet.

For information call: 519-649-1145 or visit our Website: www.thyroidlondon.ca.

Moncton

Moncton chapter's education program will be revived in May 2004. Check your newspaper, radio and cable channel for location, date and time.

For information call: 506-856-5121.

Ottawa

Location: Bickell Room, Civic Campus, Ottawa Hospital, 2053 Carling Ave at Parkdale

- Tuesday May 18, 2004. 7:00 pm. Annual General Meeting **Dr. Heather Lochnan**, Head, Endocrinology Unit, Civic Campus, Ottawa Hospital. Topic: *Thyroid Cancer*.

For more information call: 613-729-9089 or visit our Website: http://ottawa_thyroid.ncf.ca.

Toronto

The chapter is planning its spring event. For details and more information call the Helpline. 416-398-6184.

Mark your 2004 calendars . . .



Saturday morning, **June 5**
Patient Thyroid Update Forum

Saturday, **June 5**
2:00 pm
Annual General Meeting



Friday, **November 12**
2nd Annual Gala

Saturday, **November 13**
Professional Day for Family
Medicine

Chapter news

Burlington/Hamilton

The chapter continues to support the chapter Toll Free Help and Information Line. Many inquiries have been received since its inception in the summer of 2003. It can be used for update on chapter coming events, requests for educational literature, membership forms, or to request a volunteer to call you. The chapter has no paid staff, all activities are provided by volunteers working from their own homes. Our volunteers do a great job. In 2004-2005 the chapter wants to concentrate on raising funds for thyroid disease research. We believe there is a great need to increase research in all areas of thyroid disorders. If you agree, we have lots of ideas, just need the volunteers – anywhere from Oakville to Niagara and all points in between are served by the Burlington/Hamilton area chapter.

Kingston

Thursday, March 11, chapter volunteers, in cooperation with Anne Sylvester-Wong, territory manager of Theramed Corporation, staffed an information table at Wal-Mart Pharmacy. Many people stopped for information and literature.

Tuesday evening, April 20, chapter members and guests heard an interesting talk entitled, *Is there a role for T3 replacement in hypothyroidism?* by Dr. Katherine Kovacs, endocrinologist, Queen's University, Kingston.

April is Volunteer month so we are taking this opportunity to express our appreciation to all the volunteers whose work makes Kingston chapter successful. Thanks to Anne, Audrey, Bo, Elizabeth, Kim, Mary, Nathalie, Phyllis, Rick, who work at education meetings, in the chapter office, staffing tables at health fairs, fundraising and publicizing the work of the chapter and the Foundation. Thanks to the volunteers who come faithfully to work at bingo – Brenda, Cheryl, David, Gerry, Jacklyn, James, Jennie, Joyce, Judy, Laura, Lillian, Margaret, Nathalie, Wanda. A very special thanks to our volunteer treasurer, Bob Gifford, whose expertise keeps us on track. Bob is a Founding and Charter member of the Foundation who has served on both national and chapter boards.

Heartfelt appreciation is extended to The Wee Corner Store, whose owner,

Sandra Lecouffe, for two years plus, has directed the profits of the Nevada ticket sales to Kingston chapter.

During the year ended March 31, 2004, because of fundraising efforts and donations from members and friends, the chapter was able to contribute \$6,000 to the national education and services fund. We also raised over \$1,300 for the Diana Abramsky Research Fund.

Kitchener/Waterloo

The chapter staffed education display tables at two health fairs. The International Women's Day Health Fair was held on March 6 and Wilfred Laurier University Health Fair on March 22. There was a large attendance at both fairs, we answered lots of questions and distributed lots of educational literature – *thyrobulletins* and Health Guides.

London

Because JUNE IS THYROID MONTH the chapter will have a display for the month of June at Cherryhill Health Centre, Cherryhill Mall, Oxford Street, London. Thyroid information will be available at all times at this location.

The Central library, Galleria Mall, will have a display of thyroid literature for the month of June in the Health Section of the library.

In November the chapter is holding a bake sale, craft sale and raffle at a local hospital. Detailed information in next issue of *thyrobulletin*.

Montreal

Sincere sympathy is extended to Sharon Goodman, Montreal chapter president, and her family, upon the death of Sharon's mother, Mary Brandes.

The Montreal chapter held another very successful annual art exhibition and sale, its 8th, at the Montreal General Hospital, April 3rd to April 9th. Again this year, three paintings were donated for door prizes.

Ottawa

The chapter staffed a display booth at a Continuing Medical Education Conference at the Civic Campus of the Ottawa Hospital on Friday March 5th. This was a wonderful opportunity to interest fam-

ily physicians in the Foundation and its work. Two interesting and well-attended education meetings were held: On March 23 the topic was: *Popping Pills – thyroid medication and interaction with other medications*, and on April 20th the topic was *The 'eyes' have it – thyroid eye disease – its cause and treatment*.

Sincere sympathy is extended to Diane Patching and family of Dundalk, Ontario, upon the death of Wally Patching, Diane's husband, January 3, 2004. (See *Meta-static thyroid cancer – five years later, thyrobulletin* Volume 24-2, Summer 2003).

Time To Renew?

A reminder that your membership in the Foundation, which includes *thyrobulletin* may be running out.

Please check the expiry date on the address label and renew today to ensure you'll continue to receive our informative newsletter.

You can renew your membership early, for one or two years, and donations are always welcome! You again become eligible for our monthly book draw.

Use the Membership/Donation Form on page 19 or our secure payment system at:

www.thyroid.ca/english/membership.html

Thanks for supporting the Thyroid Foundation

Prism in glasses minimizes double vision



Dagmar Van Beselaere

Dagmar Van Beselaere was having trouble with her eyes. Thinking she needed a new prescription for her glasses, she headed to the optometrist. After examining her eyes, the diagnosis was cataracts and surgery was recommended. She was shocked. Two more consultations followed with the same diagnosis but both doctors saying surgery wasn't necessary yet. Then she started to see double.

Before her next appointment, with an ophthalmologist this time, Dagmar's daughter suggested that she mention a previous thyroid condition to the doctor. Years earlier she had suffered from a thyroid illness called Graves' disease.

Graves' disease is an autoimmune disorder that affects one in every 100 people. The symptoms of Graves' disease are due to the excess amounts of thyroid hormone on body function and metabolism. Symptoms include weight loss, nervousness, irritability, intolerance to heat, excessive sweating, shakiness, muscle weakness, a rapid pulse and goitre, which is an enlargement of the thyroid.

by
Linda Watson

There are three recommended treatments for Graves' disease. One can surgically remove part of the thyroid gland, destroy the thyroid cells with radioactive iodine or take anti-thyroid drugs. Dagmar had chosen the radioactive iodine treatment and thought it would be the end of her thyroid disease.

At the ophthalmologist's she mentioned her thyroid history to him. After the examination, he told her to close one eye if the double vision was bothering her and referred her to a neuro-ophthalmologist at the University of Ottawa Eye Institute. At that appointment, a CAT scan was ordered and the doctor told her to wear a patch on one eye if the double vision was a problem.

Dagmar's life was upended with the double vision. She had lost her independence during this time and many of her regular activities were curtailed. Worst of all she couldn't read which was an important part of her life.

After the CAT scan, the doctor confirmed that she had thyroid eye disease as the scan showed swollen muscles around the eyes. About 50 per cent of Graves' disease patients suffer from eye problems due to the disease. The eyes, which bulge from their sockets are red and watery and the lids are swollen. Often the eyes do not move normally because the swollen eye muscles are unable to work properly.

Dagmar's husband researched his wife's condition and read about the use of a prism inserted in eyeglasses to minimize double vision. He suggested it dur-

ing her next appointment. The doctor, uncertain, referred her to another specialist at the University of Ottawa Eye Institute, an orthoptist-ophthalmic medical technologist who was finally able to prescribe the prism.

The insertion of a prism in the glasses of a patient with double vision realigns the eyes so that the double vision is minimized. Finally, Dagmar could throw away her patch and get back to normal living.

"This meant I was able to read again and be much more comfortable about driving. I had really lost much of my independence during this time and now I had it back," she reported.

Dagmar, a volunteer for the Ottawa chapter of the Thyroid Foundation of Canada, wrote to the Royal College of Physicians and Surgeons of Canada about her experience. "I think that all doctors, especially ophthalmologists should be aware of the use of prisms and how they can improve the quality of life for patients with double vision."

Linda Watson is a member of the Ottawa area chapter.

Iodine-free cookbook available

The Light of Life Foundation (an American organization) has created an excellent cookbook with great recipes for an iodine-free diet. Patients with thyroid cancer often have to be on a low iodine diet for a prolonged period of several weeks when they are getting tested and treated for tumours. Congratulations to the Light of Life Foundation for preparing such a wonderful cookbook. For more information contact the Light of Life Foundation at www.lightoflife.org

THE BRIDGE, publication of The Thyroid Foundation of America

Thry'vors

Annual General Meeting

The Annual General Meeting (AGM) of the Canadian Thyroid Cancer Support Group (Thry'vors) Inc. will be held on:

Saturday

May 1, 2004

9:30 am to 4:00 pm

Wellspring, Oakville, Ontario.

The detailed agenda is available on their website www.thryvors.org. For more information contact Rita Banach, President at grgr@sympatico.ca

Mailing address:

Thry'vors
PO Box 23007
550 Eglinton Avenue West
Toronto ON M3N 3A8

Women's 2004 Health Forum



(L to R) Dr. Ivy Fettes & Lottie Garfield

I believe one of the most effective ways for the Foundation to be visible is to be involved in community events. It was therefore a great opportunity when the Toronto chapter participated in the Women's Health Matters Forum and Expo on January 16, 17 sponsored by Sunnybrook and Women's College Health Sciences Centre. This is an annual event at the Metro Toronto Convention Centre, this year attracting over 15,000 visitors from Toronto and surrounding areas. Some visitors were from as far away as Ottawa and a few were from outside Ontario. There were 140 exhibits demonstrating a great variety of health services organizations on topics ranging from arthritis and breast screening to thyroid disease, relaxation massage and mood disorders. There were 40 lectures by experts in their fields such as Dr. Sheela Basrur, Toronto's Medical Officer of Health and also popular presenters and writers such as author, Marni Jackson discussing her new book on Women and Pain.

Hundreds of people stopped by our Thyroid Foundation booth requesting information and picking up our educational material. The booth was attended for two days by our knowledgeable volunteers from the Toronto chapter who answered

by
Lottie Garfield

questions and offered support. We are certainly indebted to these individuals on whom the Toronto chapter depends each year to organize and participate in this forum.

Another component of our success at such a convention is the support of the medical profession. For this event, I was very pleased to arrange with Dr. Ivy Fettes, Director of the Division of Endocrinology at Sunnybrook and Women's Health Sciences Centre, and a frequent

speaker at our Toronto public education meetings, to address a session as part of the forum's speaker series. Her topic "Thyroid Disease in Women" was appreciated and well received by a capacity audience of 250. Her interest in the Foundation and patient care has been so encouraging and we thank her most sincerely. In closing, let me express my gratitude to our volunteers and the medical community for the commitment and energy that allows us to participate in these important community events.

Lottie Garfield is the past National VP Education & Research, and currently Liaison Community Education, Toronto chapter.



Volunteers at the 2004, Women's Health Forum & Expo Booth
(L to R) Beverly Strachan, Marlene Jelski, Lottie Garfield, Ellen Garfield, Laura Mandryk & Helen Lazer (not in photo)

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.

Hashimoto's and me

You're probably still depressed, but we'll do a blood test anyway. That was how my GP informed me in November 1994 that my exhaustion could be due to something other than depression. When I rang to get the test result, I was told here was nothing to worry about. But my TSH was marginally up (5.9 mIU/L - reference range 0.5-4.0 mIU/L). I needed another test to see whether I had thyroid autoantibodies, which I did (positive thyroid microsomes, titre 6400). I had Hashimoto's thyroiditis. What did this mean for me? Nothing much, but I needed to take thyroxine for the rest of my life. When I next saw my GP, I could get a prescription for my medication. I asked him if I could collect the form that evening, so that I could start taking the medication immediately. What a relief! There was actually something wrong with me. Just knowing it could be remedied gave me an emotional lift. I was at that stage unaware that I had displayed symptoms of hypothyroidism over many years:

- My husband complained that I wanted too many blankets on our bed, and that he was getting too hot. My baths and showers were always hotter than he could stand.
- In June 1989 I had a D & C, to try to find the reason for my heavy and irregular periods. I had another such procedure in August 1994. No gynecological problems were ever found. No thyroid tests were ever suggested.
- In 1991 my daughter, then in grade 3, had to write about her mother. Her friend wrote, "My mother likes being a mum". My daughter wrote, "My mother likes to sleep".
- I had even asked my GP about the pins and needles in my fingers. He replied that it was carpal tunnel syndrome, and that I should not worry about it. Pins and needles upon waking in the morning can be symptomatic of hypothyroidism.

However, depression had been my major affliction. I suffered two nervous breakdowns, and consulted four psychiatrists between 1986 and November 1994. My first nervous breakdown occurred in August 1986 when my son was ten months old. I had been feeling down for some months, was suffering from sinusitis, feeling rotten and had to care for two children. I longed to curl up in bed, but I

couldn't. I needed mothering, but I was the mother. Unfortunately, I cracked and my GP suggested that I see a psychiatrist, who said, "You are tense and anxious, and you need to relax more". He didn't ask to see me again. This breakdown savaged my self-confidence. It took years to learn to trust myself again.

Thyroid problems commonly present between three and six months after a baby is born. About five to nine per cent of women, especially those with thyroid antibodies, present during pregnancy, then develop some thyroid problems after giving birth. My thyroid function, however, was never tested.

Recently, while going through some old photographs, I came upon some taken shortly after my son's birth and about a month before my breakdown. It seems to my untrained eye that I had quite a dis-

Living with undiagnosed postpartum thyroiditis

tinct goitre at that time which was never picked up.

Shortly after this we moved from Melbourne to Brisbane, where the temperature agreed with me more. However, I felt alone and isolated in the new city. The psychiatrist I saw was terrific. He helped me out of my own private hell, that pit full of dragons that seemed to have only a downward spiral. I asked him whether my depressive state could have a hormonal component and he referred me to an endocrinologist, who, without doing any tests, declared that I was fine.

In March 1989 I had an operation. Six days later I visited a friend. I didn't feel great, but the coffee went down well. After a while I found I could hardly move. My friend took me to see my GP. He examined me, took my temperature and blood pressure and declared I was suffering from psychogenic shock. No other tests were ordered. I was stunned. They lent us a wheel chair to get me back to the car. I have since been told that operations can trigger thyroid problems. Surgery can cause a decrease in serum Total T3 and Free T4.

We were transferred back to Melbourne on October 1990. Even though we had lived there before, I still

felt below par, but knowing my history of depression, I once again visited my friendly psychiatrist. He helped me and even suggested I attend a stress management course. But my enjoyment of life was marginal, even though I had a great husband, great kids, a lovely home and no financial worries, and my sister and her two sons were coming to stay for eight months in 1992.

My sister was recovering from lymphoma, chemotherapy and radiation treatment. It was not a great visit, even though she ostensibly made a good recovery. I was tired and irritable all the time. Then in May 1993, five months after she left us, but before I could really re-establish a good relationship with her, she died of leukaemia. I was devastated, and asked my GP if I could see another psychiatrist, whom I found to be a wonderful help. However, in August of that year I had what can only be described as another nervous breakdown, amidst the chaos of grief.

I had by now gained 14 kilos (approximately 30 lbs) in two and a half years. Okay, people with hypothyroidism apparently only put on about four kilos a year, but I had been through rather difficult times. Then friends in Sidney invited us to share Christmas 1993 with them. We had a wonderful, relaxing holiday, despite my increasing nervousness in the car. I was not comfortable in the car because, I think, my reaction times were that much slower than my husband's and I would startle him with late reactions. When we visited Darling Harbour I could hardly walk. My memories of the Powerhouse Museum are of me standing in a corner, exhausted and crying. Driving back to Melbourne through the Sidney bushfires in January 1994 didn't affect me much as I was asleep in the car most of the time. My husband visited the wineries on his own.

I retreated within myself. I had, however, recently started my Master's degree. I completed two semesters, then found I couldn't cope as I was too exhausted, so I took a break. I also felt a lump in my throat when swallowing. The ENT specialist told me it was globus hystericus (a lump in the throat caused by hysteria), and that I should try not to swallow so often. Whether I actually had a goitre then, I do not know, but it certainly seemed to go away after I started treatment with thyroxine.

continued on page 15

Then in November 1994 I was diagnosed with Hashimoto's thyroiditis. Life was looking brighter. In May 1995 I had another thyroid test. My GP expressed concern that my TSH was a little low (0.3mIU/L), but he kept my daily dose at 100 mcg. In August when I went to see him with a rotten cold, he suggested that I was running a long-term risk of developing osteoporosis by taking too much thyroxine and cut my daily dose to 75 mcg. He did so without ordering another thyroid test.

Two weeks later I collapsed. Once again I could hardly walk. For six weeks I spent almost 16 hours a day in bed. The physician to whom I was referred ordered all sorts of tests, including those for thyroid function. My thyroid function was now 9.72mLU/l. High but not excessive. Two months later, after my daily dose had been doubled to 150 mcg my TSH level was 0.21 mIU/L. I don't know what other tests were ordered, but none was positive. The physician was convinced that my problem lay with my psychological state. He concluded my difficulties were a direct result of stress caused by my much-enjoyed Master's course. The GP concurred.

I no longer consult that GP or physician, I feel that they treated me condescendingly, and that their assessments were incorrect. However, I think I understand why they latched on to my psychological state as a reason for my symptoms. Firstly, the GP did not want to admit that he had, in my opinion, erroneously lowered my dose, and secondly, I had this wonderfully long history of depression and anxiety documented by my numerous visits to psychiatrists and other medical experts, which they could use as a hook on which to hang their hats.

At this stage, however, I insisted on seeing an endocrinologist, who has kept my daily thyroxine dose at 150 mcg.

So, where did this leave me? My faith and trust in doctors was severely dented. I also felt frustrated and angry that my condition had taken so long to be diagnosed, when I had concurrently presented with a number of symptoms over the years: heavy menstrual bleeding, depression, tiredness, weight gain, a lump in my throat, hemorrhoids caused by constipation, pins and needles in my fingers, difficulty in walking and sensitivity to cold.

I have now been on a stable dose of thyroxine since September 1995. My thyroid function levels are fine. Physically I feel better than I have for years, but men-

tally there were scars. Hashimoto's thyroiditis may not be life threatening (except in extreme cases), but it certainly affects one's quality of life. I feel I was not actively involved in my own activities, those of my husband or those of my children as much as I would like to have been. We cancelled social outings and holidays because I was just too tired. The effect of the condition on my relationships was intense: my husband buried himself in his work; my daughter became rather aloof (or maybe that is just being a teenager); my son was convinced I had never wanted him as I was always so tired and distant; my sister died not knowing I was ill; and my parents and brother didn't quite know what to make of me – it seemed as if they felt my personality had taken a turn for the worse. It was also difficult to sustain friendships when you are feeling perpetually tired and irritable. So I am terrified of falling ill again. I try very hard to control my condition, instead of it controlling me.

Like all Hashimoto's sufferers, I will never know when the condition first struck – maybe in my teens – but probably after I had my children. I reckon I had it for at least nine years before it was diagnosed. I understand that the effects of undiagnosed hypothyroidism come and go, and that it is essentially difficult to diagnose, but it would have been helpful to know sooner. My family and I would then have been spared a great deal of anxiety, stress, medical treatment and expense. I have at times felt that my husband and children were robbed of an effective wife and mother for many years.

I believe in obtaining reliable information about my condition so I can learn how to live with Hashimoto, my autoimmune disease. I believe that awareness of thyroid disease should be raised among the general public and doctors alike. It would be good if people could be diagnosed earlier, so they do not have to wander about the medical wilderness for years, as I feel I have had to.

I submitted my Master's thesis in June 2000, and am now awaiting the result. It took six and a half years to complete a four year course. My thyroid condition contributed in no small measure to the length of time it took. But submitting it brought a great sense of relief and a feeling that this difficult period of my life was now behind me.

Reprinted with permission from THYROID FLYER, newsletter of Thyroid Australia.

With respect to volunteers . . .

- Volunteers do their tasks because they want to, not because they have to. Their interest should be respected.
- Volunteers do their work for a variety of reasons - challenge, duty, necessity, even guilt. Their reasons should be respected.
- Volunteers bring many skills to their work. Their talents should be respected.
- Volunteers often volunteer in more than one organization, therefore have their own schedules to meet. Their schedules should be respected.
- Volunteers have lives other than volunteering. Their lives should be respected.
- Volunteers do not seek payment, but neither should they be expected to pay for volunteering. Their willingness should be respected.
- Volunteers may not seek recognition, but they do appreciate thanks. Their contributions should be respected.
- Volunteers come with many personalities. Their differences should be respected.
- Volunteers may be reluctant, so they may be encouraged. But if they have difficulty in saying "No" their answer should be respected without pressure.
- Volunteers come and go. Their decisions should be respected.

Don Macnamara, 2001.

Reprinted with permission from the author and The Compass, newsletter for volunteers of The Marine Museum of the Great Lakes, Kingston, Ontario.

Quality of life of hyperthyroid patients

Quality of life is obviously an important matter for patients and is becoming increasingly recognized as an issue within the medical profession. There is relatively little information on the quality of life in UK patients with an overactive thyroid gland, therefore we felt there was a need to get the views of our patients attending the Royal Victoria Infirmary outpatients department, with the long-term aim of designing a questionnaire asking patients about their quality of life.

Patients were asked at the end of their appointment with the consulting endocrinologist if they would agree to take part in an interview, lasting approximately thirty minutes, aiming to cover all the important issues to them. This included information regarding how they felt physically (sleep, energy, restlessness, physical strength, leisure pursuits, steadiness), how they felt within themselves (self image, body size, attractiveness, heat tolerance, control of body presentation), their social life (effects on everyday life, limitations compared with previously, work, relationships, clothing, financial issues), and how they felt psychologically (tolerance for other people, nervousness, anxiety, tearfulness, thoughts about their condition, feelings about the future, confidence, anger, depression).

Eighteen interviews were conducted in total, with fifteen women and three men. The results showed that the major issue with most patients was frustration or tiredness, lack of sleep and lack of energy. Physically, patients found the weight fluctuation disturbing and often received negative comments from other people regarding their weight. Most patients expressed irritation at feeling hot all the time and excessive sweating.

Socially, some patients were upset over absence from work, either because of the symptoms they were experiencing or through treatment. Many patients found that their social life diminished, as they were feeling conscious about their appearance, especially if they had problems with their eyes. Patients also experienced difficulty with family relationships and

by
Naomi Winn

relationships with work colleagues, as a result of feeling more irritable and lacking in patience. Interestingly, one patient experienced discrimination when seeking work, owing to lack of knowledge and prejudice from potential employers regarding the medication.

Many patients were embarrassed by one or more aspects of their overactive gland. Often this was because of protruding eyes, a large goitre, or lump in the neck, embarrassment over trembling and shaking, excessive sweating, hair loss and

It is important for the medical profession to appreciate how an overactive thyroid gland affects a patient's quality of life.

marked weight loss. Patients sometimes attributed their symptoms to other things, such as the menopause, old age, or other illnesses that they had.

Psychologically, the striking feature was that patients reported crying more often than usual, a feeling of depression and a changeable emotional state. Many patients were anxious, either generally, or about their overactive thyroid gland. Worry featured highly, with the main worries being that the patients' symptoms may have been because of cancer, heart disease or other serious illness. Other patients were worried that there was something wrong with them and they could not locate what it was, or they were going out of their mind" or "crazy".

Some of the issues that patients reported were unpredicted, such as the fear of serious illness, especially cancer. Also what was surprising was how little some

patients were affected by the condition, despite having a massively overactive thyroid gland.

Our results show that there are many issues in patients with an overactive thyroid gland, some of which do not become apparent during the medical consultation. It is important for the medical profession to appreciate how an overactive thyroid gland affects a patient's quality of life, to help understand the patient as a whole person and hopefully tailor their treatment towards optimizing their quality of life.

Naomi Winn is a fourth year medical student at the University of Newcastle, United Kingdom (UK). She recently carried out this research in conjunction with Dr. S. Pierce, Consultant Endocrinologist, and the endocrinology department of the Royal Victoria Infirmary, Newcastle upon Tyne.

Reprinted with permission from BTF News, publication of The British Thyroid Foundation.

Volunteers wanted

Dr. Katherine Kovacs, an endocrinologist at Queen's University is looking for volunteers to participate in an upcoming trial of combination T3/T4 therapy in patients with hypothyroidism.

To qualify, you must have T4-treated (Eltroxin or Synthroid) hypothyroidism of at least six (6) month's duration and significant ongoing symptoms of hypothyroidism (i.e. fatigue and cold intolerance) despite being told your TSH levels are now normal.

If you qualify and would be able to commute to Kingston for clinic appointments, please contact Dr. Kovacs's office at (613) 544-3400 ext 2347.

Subclinical hypothyroidism

Thyroid disease is very common. Approximately 5% of women around menopausal age have been treated for hyperthyroidism, or have taken thyroxine medication for hypothyroidism. In fact, in Sweden, 10% of women of this age have consulted their doctors for thyroid-associated problems.

Among adults in a country with adequate iodine supply, spontaneous primary hypothyroidism occurs because of failure of the thyroid gland, but with no previous history of thyroid disease. This spontaneous hypothyroidism is virtually always of autoimmune origin and is thus called an autoimmune disease.

Thyroid autoimmune disease can be detected by the presence of thyroid antibodies. The most important antibody is directed towards the enzyme thyroperoxidase, a key enzyme in the synthesis of thyroid hormones in the thyroid gland. These peroxidase antibodies are commonly abbreviated as TPOAb. They are found in approximately 15-20% of the female population, and are probably more common in countries with a high intake of iodine. They are less common in males. In most cases, their presence indicating thyroid autoimmune disease is not associated with any symptoms at all. Nor is it associated with any of the symptoms commonly related to an inflammatory process in the body, such as fever or increased erythrocyte sedimentation rate. This stage of thyroid autoimmune disease may be called "symptomless thyroid autoimmune disease". But regardless of the lack of symptoms, the autoimmune condition in itself may be of clinical importance and must be at least considered.

Stages of progression

In some cases, more with increasing age, the disease will progress to a stage where the synthesis of thyroid hormones in the thyroid gland is affected by the autoimmune disease. This change in production of thyroid hormones will be recognized by the pituitary gland, which in turn will increase production of thyroid stimulating hormone (TSH). Biochemists call this a "feed-back system". We will now see an increase in the TSH level. This condition when the TSH is above the reference interval (or normal value) but with normal thyroid hormones (total and free T4 and T3) is commonly named *subclinical hypothyroidism, a condition with no symptoms, thus subclinical*. The disease

by
Ernst Nystrom, MD

may proceed to a stage where TSH is even more increased, the free T4 levels are low. Mild symptoms of hypothyroidism appear and later more pronounced symptoms, low free T4 and T3, overt hypothyroidism. Approximately one in 10 women with the presence of TPOAb will progress to mild/overt hypothyroidism. Thyroid disease may progress through these stages: symptomless thyroid autoimmune disease, subclinical hypothyroidism, mild hypothyroidism and overt hypothyroidism.

Hidden symptoms

The expression subclinical thyroid disease has, until recently, been regarded as indicating a clinical asymptomatic condition defined by certain laboratory findings:

- Subclinical hypothyroidism: Increased TSH, with normal thyroid hormone levels;
- Subclinical hyperthyroidism: Low TSH, with normal thyroid hormone levels.

Today we realize that many individuals with laboratory findings indicating subclinical thyroid disease, with *no* apparent symptoms, do in fact *have* symptoms. In addition, many individuals with subclinical thyroid disease who appear healthy may be at risk of later developing cardiovascular disease or respiratory ailments.

I will here describe some aspects of subclinical hypothyroidism, the condition in which the individual has an increased TSH and normal thyroid hormone (usually free T4) concentration. Subclinical hypothyroidism is more common in women than in men, at least up to the age of 70 years. It increases with age from 2-3% at age 50 to 10% at age 70. The condition is more common in iodine sufficient areas.

Risk: contributing conditions

Certain conditions increase the risk of developing subclinical hypothyroidism:

- Presence of thyroid antibodies TPOAb;
- Treated Graves' disease;
- Irradiation;
- Prescription drugs and other medications: amiodarone, lithium, iodine, interferon-alfa;

- Recent pregnancy;
- Other autoimmune diseases;
- Relatives with thyroid or other autoimmune diseases.

If any of these conditions can be detected, a doctor's alarm bell should go off.

Subclinical hypothyroidism may progress to a state where the symptoms and signs are more typical of thyroid dysfunction, mild and overt hypothyroidism. Such symptoms are: dry skin, slow speech, edema of the eyelids and face, feeling cold, decreased sweating, pronounced tiredness, hoarseness, etc. The very presence of thyroid antibodies (TPOAb) means the risk of the condition progressing is increased.

- In some cases the TSH level remains stable, and the individual remains euthyroid.
- The higher the TSH, the larger the risk for progression.
- Increased TSH + TPOAb, women 4.3%/year.
- TSH>10-12 mU/L high risk.

How to proceed

Many symptoms found in subclinical hypothyroidism are vague and difficult to associate directly with thyroid disease. A patient may complain of feeling a bit tired – "something is wrong", slightly depressed, dry skin, impaired memory and constipation.

If an individual with subclinical hypothyroidism has symptoms indicating lack of thyroid hormone, the best way to investigate is to treat the patient with thyroxine for about six months. The doctor can then decide if the symptoms have disappeared. Four such double-blind studies have been carried out. They show that approximately one individual in four with subclinical hypothyroidism has such symptoms which will improve with thyroxine treatment.

Blood lipids may be affected in subclinical hypothyroidism. One investigation which summed up the results of many studies (the so called meta-analysis) showed serum cholesterol decreased with a mean of 0.2 nmol/L when thyroxine was given to individuals with subclinical hypothyroidism.

Other systems affected

Subclinical hypothyroidism also af-

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fects the cardiovascular and respiratory systems. After treatment with thyroxine, however, individuals with subclinical hypothyroidism will improve their heart function and their ability to exercise. Subclinical hypothyroidism may also be important for the brain and neuro-muscular system. Some symptoms related to these systems have improved after thyroxine treatment. The symptoms may be related to the systems involving muscular and cognitive dysfunction (as found in memory and similar tests) and depression.

Finally, subclinical hypothyroidism may have important effects on fertility and pregnancy. Fertility is decreased in a patient with subclinical hypothyroidism. Even more important, thyroid dysfunction in subclinical hypothyroidism may be-

come more pronounced during pregnancy. This may affect the neuropsychological development of the unborn child. The child of a mother with undiagnosed subclinical hypothyroidism may later not perform as well in school as it would have had the mother received thyroxine during pregnancy.

Early warnings

The finding of a raised TSH - or even high/normal TSH with normal thyroid hormones - may be of clinical importance more often than previously thought, especially for pregnant women, but also as an underestimated risk factor for cardiovascular disease. In subclinical hypothyroidism simply a loss of quality of life is an early sign, stressing that we must do thyroid tests on wide indications, even if the patient has only vague and unspecific complaints.

We, as physicians, would do well to listen to our patients' complaints. They are the ones who first recognize the symptoms below the surface.

Professor Ernst Nystrom practices and teaches in the Department of Endocrinology at the Sahlgrenska University Hospital and at the Sahlgrenska Academy of Gothenberg University, Sweden. As chairperson of the local organizing committee for the European Thyroid Association (ETA) Conference in Gothenberg, he was very busy but took time to give Thyroid Federation International (TFI) members a special presentation that shed light on a thyroid condition without symptoms. His geniality and concern for his patients were readily apparent. He is a doctor who listens.

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