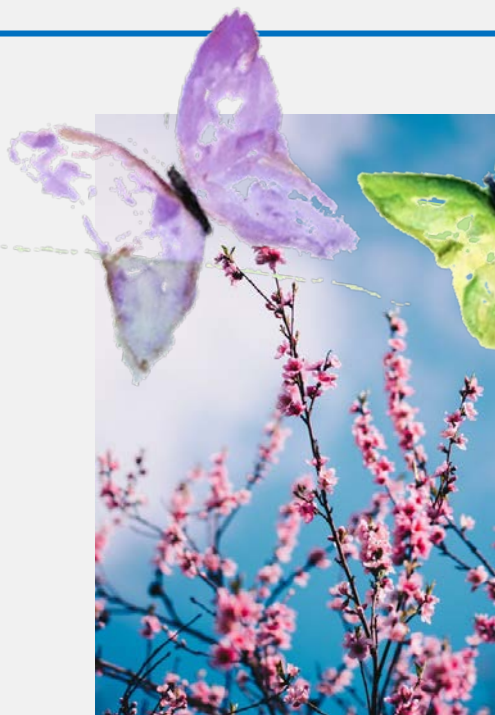




Thyrobulletin

Spring 2019



*June is Thyroid Month
in Canada!*

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CANADA'S FOOD GUIDE 2019

WHAT'S NEW?



39th ANNUAL GENERAL MEETING

JUNE 22, 2019

TORONTO



PATIENT STORIES

Meet Judy, Lauri, and Tracy



Thyroid Foundation of Canada
La Fondation canadienne de la Thyroïde



June is Thyroid Month in Canada!



FOUNDER / FONDATRICE
Diana Meltzer Abramsky, C.M., B.A.
1915 - 2000



The Voice and Face of
Thyroid Health in Canada

La voix et le visage de la santé
thyroïdienne au Canada

Thyroid Foundation of Canada
La Fondation canadienne de la
Thyroïde

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2018-2019

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Thyroid Foundation of Canada
P.O. Box 298, Bath ON K0H 1G0
www.thyroid.ca
800.267.8822

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

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From the Editor

Dear Readers,

It's Spring!! Most of us have been waiting a long time for Spring and better weather after a long drawn-out winter. As I write this the sun is shining brightly and the temperatures are a few points above 0 degrees – yeah!!! Keep going up, warmer temperatures and more pleasant days ahead.

I have been involved with Thyroid foundation of Canada since 1990 and have gained a lot from this organization regarding Thyroid disease and have provided help to those who have had a lot of frustrating times with their own condition (you will find a story in each edition). In this edition there are three stories and I encourage you to read them all so you'll see how others have had a difficult journey with thyroid disease and maybe you have too. This might be my last year participating with the national board, (I've served in many different positions); after all when you do the math 29 years is a long time and it's time to look at moving on, give room for new blood and new ideas.

There's lots happening at TFC and with better weather it will give us a boost and inspire us to be more enthusiastic. Let's see what we have been up to – lots of work in Advocacy with the Government of Canada, Health Canada, the Medical Community and like-partners relating to Thyroid disease. We have been lobbying for quite some time for support in some of those areas and this year our president, Laz, who lives in Ottawa was persistent enough and had the availability to make some inroads. We look forward to more progress in the near future.

As with every year there's an AGM, there will be Nominations for others to get involved with the organization. Give it some thought or maybe find someone who could be an asset and encourage them to be nominated. We'd love to see you attend.

Thyrobuletin is for you, to keep you informed and let you know what is happening at TFC. Contributions and ideas from you and others are always welcome and a great addition to the newsletter. Let us know how you feel about this edition. How can we improve, do things better or differently that will be of benefit to everyone?

Wishing you a great spring and summer with beautiful flowers blooming and nice sunny warm days – well at least most of the time.

Mabel Miller



Thyrobuletin Committee/comité du Thyrobuletin: Mabel Miller (Director, Education and Publications/ Directrice, éducation et publications); Katherine Keen (Administrative Coordinator/ Coordonnatrice administrative)
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A MESSAGE FROM THE PRESIDENT



UN MESSAGE DE LE PRESIDENTE

Dear Readers,

In the last Thyrobuletin, I wrote about the work being done on our new Advocacy Plan. I am happy to report that our plan was completed and approved by our board at our November meeting. The plan has three objectives with specific initiatives under each objective:

1. Improve thyroid patient care through advocacy with key health care stakeholders.
2. Establish strategic alliances with other charities to share information and best practices and collaborate on projects of mutual interest to benefit thyroid patients in Canada.
3. Establish research projects on patient care and thyroid statistics and leverage findings to support advocacy and relationship building initiatives.

Work has begun on the first objective and since January, we made some progress by meeting with the Canadian Society of Endocrinology and Metabolism (CSEM). This organization is key because it is a national advocate for excellence in endocrinology research, education, and patient care, and its mandate is to advance the discipline of endocrinology and metabolism in Canada. I am happy to report we established a working relationship with CSEM! TFC will provide CSEM feedback on patient issues and concerns to assist CSEM in updating their endocrine Thyroid procedures to improve Thyroid care.

Another initiative completed as part of the Advocacy Plan was the preparation of a Statement of Work to establish a Patient Care and Thyroid Research Survey Project. This research survey will leverage research findings to support our advocacy and relationship building initiatives. We are working with Statistics Canada to see what statistics we can use from their existing database.

Other highlights of the year:

- We ran our Light a Tree fundraiser again over the Christmas holiday period. Due to the hard work of Mabel Miller, Susey Harmer and Katherine Keen, we were able to increase our donations and greatly reduce our expenses for a net total of \$5,169.40.
- We have an arrangement with Mylan Canada to publish the new Thyroid educational videos they are preparing for our website. In January, we received a first draft of a 30-second video on hypothyroidism. It has been reviewed and found to be very suitable for our website and Thyroid community. We expect to receive more videos over the next few weeks.

Chers lecteurs,

Dans le dernier Thyrobuletin, j'ai parlé du travail réalisé sur notre nouveau plan de plaidoyer. Je suis heureux de signaler que notre plan a été achevé et approuvé par notre conseil lors de notre réunion de novembre. Le plan a trois objectifs avec des initiatives spécifiques pour chaque objectif:

1. Améliorer les soins aux patients atteints de thyroïde en plaidant auprès des principaux acteurs du secteur de la santé.
2. Établir des alliances stratégiques avec d'autres organismes de bienfaisance afin de partager de l'information et des pratiques exemplaires et de collaborer à des projets d'intérêt commun au bénéfice des patients atteints de thyroïde au Canada.
3. Établir des projets de recherche sur les statistiques relatives aux soins des patients et à la thyroïde et exploiter les résultats pour soutenir les initiatives de plaidoyer et d'établissement de relations

Les travaux ont commencé sur le premier objectif et depuis janvier, nous avons progressé en rencontrant la Société canadienne d'endocrinologie et du métabolisme (CSEM). Cet organisme est essentiel, car il est un défenseur national de l'excellence dans la recherche, l'éducation et les soins aux patients en endocrinologie. Son mandat consiste à faire progresser la discipline de l'endocrinologie et du métabolisme au Canada. Je suis heureux d'annoncer que nous avons établi une relation de travail avec le CSEM! Le TFC fournira des informations en retour au CSEM sur les problèmes et les préoccupations des patients afin d'aider le CSEM à mettre à jour ses procédures thyroïdiennes endocriniennes afin d'améliorer les soins de la thyroïde.

Une autre initiative achevée dans le cadre du plan de plaidoyer était la préparation d'un énoncé de travail visant à mettre en place un projet d'enquête sur les soins des patients et la thyroïde. Ce sondage de recherche tirera parti des résultats de la recherche pour appuyer nos initiatives de défense des intérêts et d'établissement de relations. Nous travaillons avec Statistique Canada pour voir quelles statistiques nous pouvons utiliser à partir de leur base de données existante.

Autres temps forts de l'année:

- Nous avons de nouveau organisé notre collecte de fonds Light a Tree au cours de la période des vacances de Noël. Grâce au travail acharné de Mabel Miller, Susey Harmer et Katherine Keen, nous avons pu augmenter nos dons et réduire considérablement nos dépenses pour un montant total net de 5,169,40 \$.
- Nous avons un accord avec Mylan Canada pour publier les nouvelles vidéos éducatives sur la thyroïde qu'ils préparent pour notre site Web. En janvier, nous avons reçu une première version d'une vidéo de 30 secondes sur l'hypothyroïdie. Il a été examiné et



- The Local Area Support concept described in the last Thyrobuletin is starting to catch on. We first received interest from our Treasurer, Deb Walker, to schedule a public education meeting in Brandon, Manitoba. More recently, Tracy Hey, a member of our Help Line Team, volunteered to be the Local Area Public Education Coordinator for Halifax. She is planning for the first meeting in the fall! Mabel Miller, with her many years of experience in public education, will be supporting her.

We are looking for volunteers to take on board positions in several areas such as Public Relations, Thyroid Research, Volunteer Recruitment and Development and Local Area Development. Additionally, we are looking for volunteers to work on our Help Line, provide Facebook site support, and help manage our new Patient Forum. The more volunteers we have, the more we can achieve!

If you would like to become a volunteer, please contact us at 1-800-267-8822 or by email at info@thyroid.ca

jugé très approprié pour notre site Web et la communauté thyroïdienne. Nous prévoyons recevoir plus de vidéos au cours des prochaines semaines.

- Le concept de soutien local décrit dans le dernier Thyrobuletin commence à faire son chemin. Deb Walker, notre trésorière, nous a tout d'abord intéressés à organiser une réunion d'éducation publique à Brandon, au Manitoba. Plus récemment, Tracy Hey, membre de notre équipe de téléassistance, s'est proposée pour être la coordonnatrice locale de l'éducation publique à Halifax. Elle planifie sa première réunion à l'automne! Mabel Miller, avec ses nombreuses années d'expérience en éducation publique, la soutiendra.

Nous recherchons des volontaires pour occuper des postes dans plusieurs domaines tels que les relations publiques, la recherche sur la thyroïde, le recrutement et le développement des volontaires et le développement local. De plus, nous recherchons des volontaires pour travailler sur notre ligne d'assistance, fournir un support au site Facebook et aider à gérer notre nouveau forum des patients. Plus nous avons de volontaires, plus nous pouvons accomplir!

Si vous souhaitez devenir bénévole, veuillez nous contacter au 1-800-267-8822 ou par courriel à l'adresse info@thyroid.ca.

Help Line Summary Report

by Laz Bouros

We are glad to announce that the work of the Help Line Team has taken on an even more important role in supporting Thyroid patient care! Due to recent discussions with The Canadian Society for Endocrinology and Metabolism (CSEM), TFC will provide CSEM feedback on patient issues and concerns. This valuable feedback will assist them to update their endocrine Thyroid procedures to improve Thyroid care. This is part of their mandate.

The first set of feedback information we provided to CSEM is a new Help Line Call Statistic Summary Report sourced from our Help Line calls over the past year. We grouped the calls we received into seven difference categories or topics. We expect the seven initial topics to be refined over the next few months. This information will help showcase Thyroid patient issues and concerns and improve Thyroid patient care in Canada. No detailed caller data will be disclosed.

TFC Help Line Summary Report April 2018 - February 2019

List of Topics	Per Cent
1. Specialist/Referral - Wants a list of endos; wants us to recommend a doctor; their GP won't refer them.	9.9%
2. Medications/shortage - Can't get Thyroid etc. from their pharmacy; where can they get some; when will it be available?	11.3%
3. Info about condition - Has been diagnosed and wants more information about treatment etc.	29.6%
4. Support group/Chapter - Is there a support group or chapter in my area?	7.0%
5. Lab test questions – TSH, T4, T3 and other Thyroid testing.	9.9%
6. Treatment Issues - Treated but still not well.	22.5%
7. Volunteering/ Interest in TFC - Interested in being a volunteer; wants to know more about TFC.	9.9%



April 7 – 13 is National Volunteer Week

A BIG THANK YOU TO ALL OUR DEDICATED VOLUNTEERS!



39TH ANNUAL GENERAL MEETING

39ÈME ASSEMBLÉE GÉNÉRALE ANNUELLE

THYROID FOUNDATION OF CANADA

39th ANNUAL GENERAL MEETING

June 22, 2019
9:00 am - 12:00 pm

Four Points by Sheraton Toronto Airport



6257 Airport Road
Mississauga, ON

LA FONDATION CANADIENNE DE LA THYROÏDE

39ème ASSEMBLÉE GÉNÉRALE ANNUELLE

le 22 Juin, 2019
De 9h00 à midi

Members of the public are welcome to attend.

Members of the Thyroid Foundation of Canada are entitled to vote.

Les membres du public sont invités à y assister.

Les membres de la Fondation canadienne de la Thyroïde ont le droit de voter.

Planning is in progress. An afternoon public event may be held. Please check back at thyroid.ca

JOIN US!

La planification est en cours. Un événement public l'après-midi peut avoir lieu. S'il vous plaît vérifier à : thyroid.ca

Register by email: info@thyroid.ca or call 1-800-267-8822

Thyroid Foundation of Canada CALL FOR NOMINATIONS 2019 - 2020



La Fondation canadienne de la Thyroïde APPEL DE CANDIDATURES 2019 - 2020

The National Board is accepting nominations for positions on the Board for the coming year 2019 -2020.

As per the By Laws, Article No. 17 (a) **a. Number of Directors.** The Board shall consist of a minimum of five (5) directors and up to a maximum of twelve (12) directors elected by the membership plus the immediate past-President if s/he agrees to serve. If vacancies exist on the Board, the Board may appoint directors up to a maximum of one-third of the Board. The term of any appointed director shall expire at the close of the next general meeting.

If you are interested or know of anyone who might be interested, please contact the Nominating Committee Chair at nominations@thyroid.ca no later than **April 30, 2019** or call 1-800-267-8822.

Agenda and more details to follow: [Nominations 2019-2020](#)

Nominating Committee/ Comité de nomination: Mabel Miller, Kim McNally, Susey Harmer

Le conseil d'administration national accepte les candidatures aux postes du conseil d'administration pour l'année à venir 2019-2020.

Conformément à la réglementation, article n ° 17 (a) **a. Nombre de directeurs.** Le conseil d'administration est composé d'un minimum de cinq (5) administrateurs et d'un maximum de douze (12) administrateurs élus par les membres, plus le président sortant si celui-ci accepte de siéger. S'il y a des postes vacants au sein du conseil, celui-ci peut nommer des administrateurs jusqu'à un tiers du conseil. Le mandat des administrateurs nommés expirera à la clôture de la prochaine assemblée générale.

Si vous êtes intéressé ou connaissez quelqu'un qui pourrait l'être, veuillez contacter le président du comité de nomination à nominations@thyroid.ca au plus tard le **30 avril 2019** ou composer le 1-800-267-8822.

Ordre du jour et plus de détails à suivre: [Nominations 2019-2020](#)



QUESTIONS AND ANSWERS on Thyroid Cancer

Q: Does smoking or drinking cause thyroid cancer?

A: Smoking and drinking are not related to thyroid cancer. Such habits of course are better avoided for overall good health but they neither cause nor aggravate the course of thyroid gland malignancy.

Q: Does thyroid cancer spread throughout the body and how can you tell if this is so?

A: Thyroid cancer rarely spreads throughout the body. Most thyroid cancers are cured by the initial operation. Although thyroid cancer may extend to lymph glands in the neck, the removal of these lymph glands is usually quite feasible and curative. Infrequently cancers do spread to lung and bone and can be detected by x-ray and scanning imaging procedures. Such a situation requires treatment by radioactive iodine or other x-ray therapy procedures and occasionally surgical removal. For the rare but more aggressive types of cancer, treatment with chemotherapy and x-ray therapy may be recommended.

Q: How likely are my chances of dying of thyroid cancer even with all this treatment?

A: Other than skin cancer, the most common types of thyroid cancer have the best long term outcome when promptly treated compared to all other types of cancer. The majority of patients are totally cured by treatment.

Q: How is thyroid cancer detected?

A: Thyroid cancer is frequently detected by the patient becoming aware of a lump in the neck. Half such cases are detected by a physician during a routine physical examination for an unrelated problem. Thyroid cancer does not cause pain and rarely produces symptoms. Virtually all patients with thyroid cancer have normal metabolism and thyroid tests.

Q: What are the side effects of treatment? Will I lose my voice or have a large scar?

A: The usual treatment of thyroid cancer involves the removal of at least a portion or all of the thyroid gland through a small neck incision. It is infrequent for patients to have any problem with a voice disorder or calcium imbalance as a consequence of the surgery. The removal of lymph glands may require a larger incision, but this is usually low in the neck and is still compatible with a good cosmetic result. In some cases where voice problems persist after surgery, referral and treatment by a voice therapist usually improves the situation.

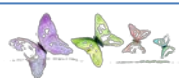
Q: What can I do to ensure that I have the very best result of treatment for my thyroid cancer?

A: It is important that nodules in the thyroid gland or in the neck area be appropriately diagnosed at an early stage. You should see your family doctor who will assess the situation and most likely refer you to the appropriate specialist to confirm the diagnosis and administer the correct treatment. Early detection and treatment almost always results in a complete eradication and cure!

Information contained in this article was updated in May 2010 by Hortensia Mircescu, MDFRCPC, Endocrinology Division, Centre Hospitalier de l'Université de Montréal, Assistant Clinical Professor, Faculty of Medicine, Université de Montréal. Note: More up to date information will be provided when available. Any further questions, please contact us at info@thyroid.ca or 1-800-265-8822. <https://thyroid.ca/resource-material/information-on-thyroid-disease/thyroid-cancer/>

THYROID MONTHS – A Year of Thyroid Topics
Every month we are featuring a topic on Thyroid Disease at thyroid.ca
APRIL IS THYROID CANCER MONTH

April 2019	Thyroid Cancer	July 2019	Thyroid Disease and Seniors
May 2019	Thyroiditis	August 2019	Thyroid disease and Mental Health
June 2019	Surgical Treatment of Thyroid Disease	September 2019	Thyroid Disease... Overview of Thyroid Function



An apparent epidemic of thyroid cancer due to overdiagnosis

Dawnelle Topstad MD MPH, James A. Dickinson MBBS PhD, University of Calgary

The apparent numbers of diagnosed thyroid cancers (incidence rates) are increasing in many high-income countries.¹⁻³ Most of this increase is due to papillary thyroid cancer,¹⁻³ which generally has an indolent course. Only a small proportion of these cancers behave aggressively and very few patients die of them, unlike some of the other types of thyroid cancer.⁴

We therefore examined Canadian provincial and national data from 1970 to 2012 to understand what is happening in this country. Data was obtained from: Statistics Canada, and the Canadian Cancer registries.

Apparent thyroid cancer incidence rates have increased over 5 times in the past 20 years, especially in women. (Fig 1) Thyroid cancer is now the fifth most common cancer in women, sixteenth in men. However, the survival ratio is now over 98% for women and 95% for men.⁵

Most cancers become more common with age. This used to be the case for thyroid cancer, but now the highest rates and most of the increase in incidence is among 40-60 year-old women (Fig 2). Incidence rates in men vary less, and thyroid cancer death rates have barely increased at all. The increase in incidence varies widely among provinces, with no relationship to any known causes of cancer.

The only reasonable explanation for the increase and wide variation in incidence rate is different practice patterns and overdiagnosis. This overdiagnosis results from excessive use of thyroid ultrasound and other imaging, with over-identification of small cysts in the gland. Biopsies from small cysts are hard to interpret, and may be called cancer when they will not behave like cancers at all.

We therefore recommend that doctors should reduce overuse of diagnostic imaging, and support research to identify patients with indolent thyroid tumours, while still identifying aggressive thyroid cancers that need treatment. We should be very cautious about labelling people with trivial changes as cancer, given the consequences for their lives from operations, and lifelong follow-up and treatment.

Read this article in full at:

https://www.researchgate.net/publication/319124050_Thyroid_cancer_incidence_in_Canada_a_national_cancer_registry_analysis

Have you given any thought to leaving a Bequest to TFC?

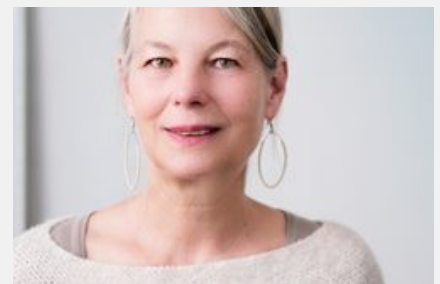
TFC has been fortunate to receive several bequests recently for Thyroid Research. Important though research is, we are also in great need of funding to continue and expand our awareness and support programs. You can make a lasting difference and help other thyroid patients!

By including the TFC in your will, your gift will help achieve the following:

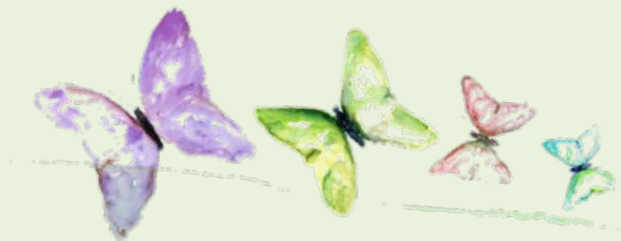
- Raise awareness and **reach more thyroid patients**
- Impact the **medical profession**, the government and the public
- Accomplish **earlier diagnosis** for thyroid patients and providing education on the best treatments
- Receive **significant tax benefits** for your personal estate

With this gift, you can make a lasting impact for those suffering from thyroid disorders.

Contact us for more information: 1-800-267-8822 info@thyroid.ca



June is Thyroid Month in Canada!



Help celebrate **“June is Thyroid Month”**

INFORMATION ON ALL THYROID CONDITIONS

Hypothyroidism • Hyperthyroidism • Graves' Eye Disease

Thyroid Nodules • Thyroid Cancer • Surgical Treatment of Thyroid disease

Thyroid Disease in Childhood • Thyroid Disease in Pregnancy • Thyroiditis

Spread the word about what can be found with **Thyroid Foundation of Canada!!**

Our website: **www.thyroid.ca** Facebook: **Thyroid Foundation of Canada**

Help Line: 1-800-267-8822 or info@thyroid.ca

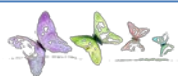
Important: The thyroid controls the way your body uses energy.

Help us to get information on Thyroid disease to others. Got an idea? - Get in touch!

Fundraise – Distribute brochures – Join our team



We welcome others who can help with the work we do. Let's chat.





It's OPEN HOUSE for Nominations!!



Nominations means you can get involved and help make a difference in the **lives of thyroid patients**. The door is open, so drop in (info@thyroid.ca or 1-800-267-8822)

Every year the **Thyroid Foundation of Canada** gives opportunity to anyone who has a willingness to help others to become involved.

Every year at our **Annual General Meeting** there's opportunity for those interested to be elected to the National Board or participate as part of a committee.

Meet people, meet patients with stories to tell, create new friendships from coast to coast, gain new experiences while helping others.

Help us to Help you or maybe someone close to you!!!

Contact us at info@thyroid.ca or 1-800-267-8822.

For more details on Nominations see page 5 of this edition.



Thyroid Foundation of Canada
La Fondation canadienne de la Thyroïde

Bus. No. 11008 4622 RR0001

THE MANY FACES OF THE THYROID

Thyroid patient groups in countries around the world are participating in **International Thyroid Awareness Week (ITAW)** activities during the week of May 25-31, 2019. This year's theme is **The Many Faces of the Thyroid**, in recognition that Thyroid Disease has many forms and affects any age, as well as the people who are close to thyroid patients.

In honour of this year's ITAW theme, the following pages present Three Faces; three compelling stories from thyroid patients.

Judy, a TFC member, and two of our Help Line Team members, Lauri and Tracy, share their thyroid journeys, in hope they will help others going through similar difficulties.

We hope you enjoy reading their stories and how they have come to terms with their lives as thyroid patients.

INTERNATIONAL THYROID AWARENESS WEEK MAY 25-31, 2019



Theme: **The Many Faces of the Thyroid**

For more information on ITAW, visit thyroidweek.org



Judy: It's not my fault!

By Judy Edgar

The phone rang. It was 6 pm and we were just about to sit down to dinner. It was my doctor! I had been to her office that morning complaining that my hands were so cold I was unable to touch my own body. It was like they were constantly in a freezer. I went to have my blood work done right from my appointment and here was my doctor calling me just a few hours later. "Your blood test shows you have a hypoactive thyroid and you need to go on medication immediately!" I hung up the phone and started to cry. I knew that one symptom of this disease was the inability to lose weight. This was why no matter how little I ate or how much I exercised I couldn't lose any weight. It's not my fault!

This was 1987 and I was 36 years old. I went on levothyroxine and have been on it since then. As time went by I started to ask a lot of questions. Before being diagnosed, I had been scheduled to have stomach bypass surgery because I couldn't lose weight. Fortunately I got scared and backed out. One year before my diagnosis I had miscarried twins. After my diagnosis I learned it was difficult to get pregnant and maintain a pregnancy if you have thyroid disease. I also learned that some symptoms of a hypoactive thyroid disease were brain fog, fatigue, restless leg syndrome, constipation, back problems and depression. I had all of these and had just accepted this as part of life.

In 2009 I started my own business, a Curves for Women franchise. I met so many women who had hypoactive thyroids. I also met women who suffered many of the symptoms but went undiagnosed. I continued to study more and learned that the medical profession only diagnosed someone having a hypoactive thyroid if one's TSH levels are above the normal range of 1-5. I learned that there hadn't been any updates on how thyroid disease was diagnosed and treated since 1970 and there has been little research done in spite of the growing numbers of people (mostly women) suffering.

I delved into more research once my daughter started to show signs of a problem with her thyroid. She suffered from severe depression with suicidal thoughts, gained weight, was cold all the time, had brain fog and had difficulty making it through a day of work.

One day I had an epiphany! Maybe I had been dealing with thyroid disease since I was 19 months old when I had a tonsillectomy. Up until I had my tonsils removed, my mother

told me I had been a very tiny baby. After my tonsils had been removed I became a chubby child and when I was 8 years old I weighed 98 pounds and the doctor put me on a diet. I was slow and clumsy and I felt I was a big disappointment. As a teenager I went to weight watchers and tried many other diets. I got married and at my wedding weighed 170 lbs. which is probably the least I ever weighed in my adult life.



When I was 16 I developed back problems and by the time I was 23 the pain was severe and I was diagnosed with a ruptured disc which was surgically removed. I now know that thyroid disease can cause back problems (my daughter suffers from low back issues). As a result of this surgery I developed scar tissue which impinged my sciatica nerve resulting in permanent nerve damage and drop foot.

Although I have suffered I am grateful because my problems have led me to research and my daughter returned to school to become a holistic nutritionist. Since becoming an RHN one of her main specialties has been researching thyroid disease. Between the two of us we have learned so much that we didn't know before and that the medical profession does not accept as it hasn't been scientifically proven and they are working with old science. My belief is that the pharmaceutical industry is not interested in looking for alternatives as Levothyroxine was the most commonly prescribed medication in the United States as of 2016, with more than **114 million** prescriptions. There is too much money being made from this drug to try to find alternatives.

I have changed my diet and eat a mostly paleo diet that does seem to help. I also take zinc and selenium supplements. Recently I asked my doctor to include checking my T4 and T3 levels when he sent me to check my TSH. He didn't think it was necessary but appeased me.

I am grateful that the laboratories now give the opportunity to check our lab results online and I discovered that my T3 levels were very low and T4 levels were high. The active hormone is T3 and the thyroid converts T4 to T3. My results led me to believe that I wasn't doing the conversion very well. When I questioned my



doctor his response was that you can't depend on blood tests! But, what if the results are accurate? I checked with my pharmacist who told me that T3 drugs are available but she has been running her own pharmacy for over 6 years and has never received a prescription for T3. What you may not know is that our TSH may be good but if the message to the T4 hormones is not getting through to convert to T3 we are still suffering. Then I asked an endocrinologist about taking desiccated thyroid hormone and I was told it contained T3 and that wasn't necessary because T4 converts to T3 and I could end up with too much T3. So here I am dealing with fatigue and struggling with weight and know that without T3 my endocrine system is not functioning very well. I have discovered a supplement which supports the

conversion of T4 to T3 and have been taking it for a while. I do feel less fatigued and I showed it to my doctor. He read the ingredients, handed the bottle back to me and said "Let's agree to disagree"! So where does this leave the suffering thyroid patient? I hope by writing this and with an organization like the Thyroid Foundation of Canada we can lobby for more research. I believe that with the toxicity levels in our environment more and more people, especially women, are suffering from thyroid disease and what people need to know is that the thyroid is the master gland and controls our entire endocrine system causing autoimmune disorders. Let's do what we can to eradicate autoimmune disease.

A Good Diet for Thyroid patients!

What is a good diet for those with Thyroid disease?

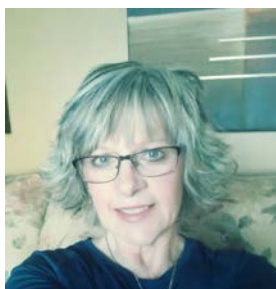
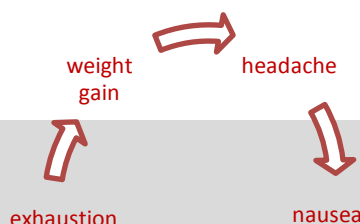
There are lots of ideas on the internet about the best diet for thyroid patients from foods that are high in iodine content to various vegetables, etc. After checking with a number of dieticians there is no one menu that is said to be best for us who have a thyroid condition. For those of us who have difficulty with weight gain there's the same answer. We are being told the best diet for anyone is to eat wisely, follow the Canada's Food Guide and now we have a new one published recently. If you haven't seen it, it would be good to take some time to review it. A sample of this is shown below.

<div>Canada's food guide</div>	<div>What's in Canada's new Food Guide?</div> <div></div>
<div>Make healthy food choices</div> <ul style="list-style-type: none">• Eat plenty of vegetables and fruits• Eat whole grain foods• Eat protein foods• Choose protein foods that come from plants• Choose foods with healthy fats• Make water your drink of choice	<div>Be mindful of your eating habits</div> <ul style="list-style-type: none">• Limit highly processed foods. If you choose these foods, eat them less often and in small amounts.• Prepare meals and snacks using ingredients that have little to no added sodium, sugars or saturated fat• Choose healthier menu options when eating out• Involve others in planning and preparing meals
<div>Read more at: https://food-guide.canada.ca/en/healthy-food-choices/</div>	



LAURI: The Hashi cycle

By Lauri Martin



I am 56 years old and cannot remember a time that I felt well. I can remember at the age of about 17 having minor and passing symptoms of exhaustion, dizziness, being so itchy, having aches and pains.

Looking back on the birth of my older children, I am not sure if I had thyroid issues or if anyone mentioned it. In 1987, after the birth of my last baby I was told I felt sick because I had postpartum thyroid issues. I was informed by my doctor that this was common and not to worry about it. At the time I had severe ear and neck pain, all over body pain, totally exhausted, dizzy, tremors and so very cold. I remember having a head x-ray to check something, which was maybe looking for a pituitary growth. There was no follow up. The cycle never ended: symptoms of exhaustion, headaches, joint pain, nausea, aches and pains, weight issues, then back to normal for a while. This plagued me for decades.

I moved to a different city in 1990 to go to college. Once a straight-A student, I could barely finish college. I had a different doctor who suggested that maybe I suffered from depression which I disagreed with. Unfortunately, I had heard the words “Nothing wrong with you” so many times that I just stopped making doctor appointments. I had become very leery of the medical field. It was so hurtful and embarrassing to have a few doctors roll their eyes when I insisted that something wasn’t right. At that time, it was different, none of us had heard about autoimmune disease or thyroid disease or at least I had not. I even had one of my bosses insisting that there was something wrong and that maybe I had undiagnosed MS because my balance was noticeably off.

I moved back to my home town in 1994. Over the years I had mentioned to my doctor having no periods for months to long/heavy periods, migraines, anxiety, maybe/maybe not depression and all the other hypo/hyper symptoms. About 1998, my original family doctor took me aside and asked if my husband and I could afford to live on one income so that I could get some rest for a while. I was just going through the motions with my children, being there for them was so hard. It is a kind of tired that you cannot describe to people. My husband has always had to be the sole support of our family.

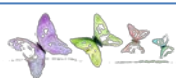
In 2002, we moved to a small rural area. In about 2004 or 2005, my sister who also has thyroid disease urged me to get my thyroid tested as I was really having a problem with exhaustion, dizziness, tremors etc. The blood tests came up fine. In March 2010, I thought I’d had a heart attack. My body stopped moving, my hands and head were shaking, I was frozen, nauseous, and the right side of my body wasn’t working right. Finally, I was formally diagnosed with overt hypothyroidism and Hashimoto’s thyroiditis. I started the process of adjusting to Synthroid. It was helping to a degree, but I find I feel best with a high free t4. My sisters are the same. Three different doctors have told me that I should have been on medication years ago. I now take a handful of other medications for neuropathy in my hands and feet. I have had a handful of other blood tests and an MRI to exclude any other autoimmune diseases. I am not diabetic, although it has been mentioned that long term untreated hypothyroidism can cause neuropathy.

Having Hashimoto’s has certainly been a struggle for me. I know that my hyper/hypo symptoms will start every January. I feel like I have the worst flu, neuropathic pain is worse, then in March and April I will flip to hypo with symptoms of sleeping all day, joint pain etc. then the rest of the year over to euthyroid with minor thyroid symptoms. Extreme heat and stress can cause me to flip to hyper. My husband and friends have told me that they always knew something was not right but didn’t know what to do about it.

Another struggle for me has been the medical field. There has never been a conversation with me about thyroid disease, so I stay on reputable websites to educate myself. For the most part I have learned not to bring up any lingering symptoms such as being so cold all the time. Being told your TSH is in range so your symptoms are dealt with is very distressing to me. I believe I deserve to have some reassurance that when working with my doctor I will be kept as symptom free as possible. In my life time I hope to see changes in how thyroid disease is viewed and treated.



Lauri and husband Dan



TRACY: A little help from my friends

By Tracy Hey

My journey with my thyroid was a surprise, an unusual and unexpected event that started in the summer of 2016. But I guess that is life, full of unexpected surprises. When I look back on it, I feel like a flow chart or road map would have been handy. It started with an episode of dizziness, a plugged ear, weird pain in my head (not like a normal headache or migraine), sensitivity to light and noise, and feeling anxious and unbalanced. I went to my family doctor to try and figure out what it was and was sent for a series of blood tests. My B12 and calcium levels came back high, so more blood tests were ordered.

In December of 2016 my lungs caught a virus and I got laryngitis in January. I missed six weeks of work and had a hard time breathing and shaking the virus. Up until this point the only thing that I caught was the common cold and flu. I was healthy, exercising and trying to eat right. My family doctor sent me off to a general medicine doctor. More blood tests were ordered and in February 2017 he discovered that my parathyroid hormone level was high, along with my calcium levels, which were possibly the early stages of hyperparathyroidism. His suggestion was to monitor for six months and if they stayed elevated to refer me to an endocrinologist. This was done and in December of 2017 I went to see an endocrinologist. At my first appointment with her, my face, neck and arms were red, dry, itchy and broken out in a rash. She referred me to a dermatologist. In December of the same year I also saw an ENT doctor for vertigo who said that the "weird episode" was a migraine, again all tests coming back as normal.

In April of 2018 I saw a dermatologist who tested me for lupus, which came back as negative. July of 2018 the dermatologist diagnosed me with cholinergic urticaria. When I sweat, my heart rate goes up and I get hot and I break out in hives and a rash. This would not have been an issue except that I was physically active taking part in about 3 long distance obstacle races a year, biking, hiking, running, boot camps and yoga.

Back to the thyroid story, during January of 2018 I was sent for a bone density scan, ultrasound and parathyroid scan. These tests found that I had a growth on my left parathyroid and thyroid. Another appointment with the endocrinologist and another ultrasound. The January ultrasound had the thyroid growth measuring 6x6 mm and was abnormal in its appearance. In June of 2018 I ended up in the hospital emergency room because I had

an asthma attack. I had exercise-induced asthma but this attack happened on my way home from work. By July 2018 the growth was 8x7 mm. And in September of 2018 I had a biopsy. The biopsy came back as inconclusive but the cells were abnormal and highly suspicious, and maybe cancer. The dreaded C word. So started my mental journey of the unknown and limbo. I already was in the "what is going on with my body" stage. What am I doing wrong? Why am I finding no answers? What did I do wrong? My endocrinologist referred me for surgery for both the parathyroid and thyroid, and as luck would have it, both were on the left side. I had no "normal" symptoms of an ill thyroid or parathyroid. But what is normal? My blood tests came back as normal and according to those results my thyroid was functioning fine. January of 2019, I met with a surgeon who was in agreement that the left thyroid and parathyroid should come out. On February 7, 2019, I had the left side of my thyroid removed.

My biggest challenge was dealing with these medical issues that all of a sudden, over 2 years, came up. I thought that there was something that I did or did not do. I went for all my normal yearly check-ups and did what healthy people were supposed to do. I had been healthy before that, visiting the doctor maybe once or twice a year. And I felt like one thing after another kept happening and there was no answer, or solution. Acceptance of what was going on and trying to figure it out was hard. I had no idea what a thyroid or parathyroid did, or what they were responsible for. Was my parathyroid and thyroid playing a part, or responsible for what was all of a sudden going on? Why was I having asthma attacks driving home in the summer?

As of today no one has said yes or no. Where to find reliable information was foreign to me. Googling thyroid and parathyroid growths is not good for anxiety levels. The good thing about the internet is the amount of information available at your fingertips, but the downfall is that not all is reliable. What is reliable and what is not? Hence my first interaction with the Thyroid Foundation of Canada. I was training and racing over 50 km a year. Exercise was my coping skill.



Post Op

Dealing with the unknown, you may or may not have cancer. What do you do with that? Luckily, I already had a strong support system, sick time, medical coverage, osteopath, massage therapist, naturopath, therapist, chiropractor, a terrific family doctor and specialists, all of whom listened and acknowledged me. But I felt betrayed by my body.

I had to get comfortable advocating for myself, asking questions no matter how silly they seemed. Before my surgery I asked the anaesthesiologist how he knew when he was going to wake me up and what happened if I had to pee during surgery. He smiled and answered my questions and treated them seriously! But I am sure he snickered inside. I had to try and figure out where to find information. Luckily, having professionals already in my life, I could get information from them or at least a starting point. And when I started sharing my story people knew people. Talking, connecting, communicating and reaching out were the best things I did. It helped me deal with the unknown and uncertainty about what was going on in my body. I also had to learn to listen to my body and respect it. If I continued to push and force it, only more damage would be done. My body was shifting and changing to a new "normal". I am learning and exploring different coping skills (meditation, mindfulness, rug hooking, and back to a yoga practice). My career for the last 16 years, answering emergency and non-emergency calls and a police and fire dispatcher - stress, 12 hour shifts and shift work.

The journey continues; as of writing this I still do not know if the growth is cancerous or not. The growth was under 2 cm, so if it is cancer we caught it early. I am learning to rest, relax, and tap into my creativity.

Accepting and embracing how my body has changed. Treating myself with kindness and compassion. If it wasn't for all of this, I would not have tried rug hooking and expanded my people circle! I have had to redefine my definition of healthy and appreciate what my body does for me, because it does a lot! I have many things to appreciate and be grateful for. And this process has been a learning experience, and a learning experience that has allowed me to meet some pretty amazing people. Life is a continuous journey full of surprises, challenges and the unknown, which is a beautiful thing. Embrace it, live and laugh often. Surround yourself with awesome people. Ask questions, communicate and fill up on positive vibes!



Tracy (centre), healing, with a little help from her friends

Tracy lives near Halifax, Nova Scotia and is planning to hold a Public Education Meeting in the near future.

Parlez anglais? - parlez francais?

Are you bilingual? – Do you have thyroid disease or know somebody who does?

Bilingual + Thyroid Disease makes for a good combination to help us with our Patient Help Line.

You could be helping someone who is French speaking, does not speak English and really needs someone to help them get a message to us or a question answered. May take up a few minutes of your time per month but you would be providing a service that could be very helpful!

We Need your Help !!!

Nous avons besoin de leur appui !!!

If interested, please contact us at 1-800-267-8822 or by email at: info@thyroid.ca



THYROID RESEARCH PROGRAM

By Laz Bouros



One of the initiatives in our five-year Strategy Plan is to create a Research Plan to establish TFC funding for Thyroid research in Canada. We now have the research funds and need to get this out to researchers. The Research Plan is next on our to-do list and we are excited about getting our research program underway!

Last fall, our Advocacy Plan identified a need for conducting a survey to acquire more information about Thyroid patient care. A Statement of Requirements was prepared for the Patient Care Research Project. The objective of the project was to conduct a research survey on the quality and quantity of Thyroid care provided by all provinces and territories and collect statistics on the number of patients affected by Thyroid disease in Canada. These requirements were driven by weakness identified from feedback received from Thyroid patients through our National Help Line, emails and Facebook site.

A first step towards implementing this project was to contact Statistics Canada to find out what information was readily available and whether Statistics Canada could expedite this project for us. We met with Statistics Canada in February. They conducted a review of their existing surveys that had Thyroid implications and contacted us with the results a few weeks later.

The 2005 Canadian Community Health Survey indicated that 7% of the population in Canada has some form of Thyroid disease. The sample was 130,000 and this translated into 9,000 respondents who had a Thyroid condition. Unfortunately, the Thyroid question was dropped from the survey after the 2005 cycle. Based on today's Canadian population of about 37 million, there's approximately 2.5 million Canadians with a Thyroid condition. While we may solicit some additional information from Statistics Canada, it looks like we will have to reach out to the private sector to implement our survey project.

Our new Research Plan will include a strategy for multi-year funding. To promote Thyroid research, we need to ensure physicians doing research have continued funding in the form of grants year after year. We would also like to establish high priority areas for research based on Thyroid patient feedback to help focus the research. These will be highlighted in our Request for Proposal for the research grants. We will need to reach out to endocrinologists to volunteer some of their time to participate in a new Peer Review Committee which will review and select the most appropriate proposals being submitted. We hope to have everything in place over the next few months and issue the first request for research proposals by next fall!

Voluntary organizational activities and peer support in Finland - how to meet new challenges?

Traditionally, organizational activities in most associations have been based on face-to-face communication and regular meetings. However, it seems that such a way of participating is no more ideal for many young and working age adults. For many of them, work and family life is energy- and time-consuming. In addition, people suffering from rare disorders often live scattered all over the country, which makes it difficult to meet in person.

At the same time, a population is aging and the number of participants in face-to-face meetings is decreasing in some areas. The majority of young people are used to utilizing the internet, including all modern means of communication, on a daily basis. So, associations also should stay up to date and offer new, modern ways of participating and peer support, including online services.

A new three-year project started in Finland

At the beginning of March 2018, the new project started at The Finnish Thyroid Association financed by STEA (The Funding Centre

for Social Welfare and Health Organisations). In Finland, STEA manages the funding granted for non-profit projects which promote health and wellbeing. For this three-year project the budget granted by STEA is 211,000€. The aim is to increase the awareness of thyroid and parathyroid diseases, especially among young and working age adults. In addition to sharing information, the project will facilitate online peer support for those in need.

To find out what kind of information is valued by the target audience, face-to-face interviews and online surveys were conducted. The result was that personal experiences from others, video lectures, short but informative video clips, professional articles, podcasts, tests and answers to FAQs would be most beneficial and desired. During the next three years such material is made available online. As a vital part of the project, online peer support such as group chats will also be developed.

Johanna Erkkilä, Project Coordinator,
Finish Thyroid Association

(From ThyroWorld, Vol. 21, 2018)



EVENTS



KITCHENER-WATERLOO

Autoimmunity and Thyroid Disease

ALWAYS HOT? COLD? TIRED? GAINED WEIGHT?

Dr. Nadira Husein, MD, FRCPC, Endocrinologist
Assistant Clinical Professor, McMaster Medical School

MAY 14, 2019

Kitchener Public Library, Main Branch

Education Table 6:00-8:45, Business Meeting 6:30,
Speaker 7:00, Question and Answer to follow

Please register: (519) 743-7502 or kpl.org

IMPORTANT DATES IN 2019


April 7-13	National Volunteer Week
May 13-19	Mental Health Awareness Week
May 25-31	International Thyroid Awareness Week 2019 This year's theme: <i>The Many Faces of the Thyroid</i>
May 25	World Thyroid Day
June 22	TFC Annual General Meeting
June 1-30	<i>June is Thyroid Month in Canada!</i>

Check for more news and events at thyroid.ca



Running out of time!?

Did your membership expire recently? If so, we are sending you this issue of **Thyrobuletin** as a courtesy. If you wish to continue receiving our newsletter for members, **please renew now!** Complete and mail this form or renew online at: <https://thyroid.ca/join/renew>

 Thyroid Foundation of Canada La Fondation canadienne de la Thyroïde		Membership/Donation Form	
Name:		Address:	
ONE YEAR: <input type="checkbox"/> Regular \$35 <input type="checkbox"/> Senior \$30 <input type="checkbox"/> Family \$45		TWO YEAR: <input type="checkbox"/> Regular \$60 <input type="checkbox"/> Senior \$50 <input type="checkbox"/> Family \$65	
MEMBERSHIP AMOUNT: \$	PAYMENT: <input type="checkbox"/> Visa <input type="checkbox"/> MasterCard <input type="checkbox"/> Cheque (payable to Thyroid Foundation of Canada)		
DONATION AMOUNT: \$	Credit Card No:	Exp Date:	
TOTAL AMOUNT: \$	Send to: Thyroid Foundation of Canada, P.O. Box 298, Bath ON K0H 1G0		CVV No.:

Thank you for your support!

