

# Thyrobuletin

Autumn 2016

## In this Issue:

- My TFC Journey
- Hypothyroidism symptoms linger despite medication use, normal blood tests
- Canadian doctors first to implant cancer patients' thyroids in their arms



Kim - my TFC journey



*It's our 6<sup>th</sup> annual Light a Tree for Thyroid campaign!*



*See insert - Please support the Thyroid Foundation of Canada*





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thyroïdienne au Canada

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La Fondation canadienne de la Thyroïde

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2016-2017

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## Contents:

Message from the President	2
Meet your new Board of Directors	3
My TFC journey	4
Hypothyroidism symptoms linger despite medication use, normal blood tests	5
Canadian doctors first to implant cancer patients' thyroids in their arms	6
News	7

*Photo p.5: courtesy of Wikimedia Hackathon 2013, Amsterdam - Flickr - Sebastiaan ter Burg (25)*

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



*A message  
from the president*



*Un message  
de votre présidente*

Hello Members from coast to coast across Canada and other countries wherever you may be.

What an exciting AGM in June 2016! It was great to see so many new faces wanting to join the National Board. Some are new and some are members who have been around before. We now have more than we've had for a long time who can contribute to the work that needs to continue.

There's no doubt, from the contacts we have, calls we receive and stories we hear, that there's lots to be done with Awareness and Education re the various types of thyroid disease. The more of you who get involved, the more information can be spread all over this country. As thyroid disease is mostly a genetic condition, sharing of information can benefit many, from your own family to friends, co-workers and beyond. It's sometimes like the grapevine effect – the message keeps going on. That's what we need to do.

Recently, it's been interesting to see new developments and new information about what's happening through research and science with thyroid conditions. You will see some of those articles in this newsletter.

The National Board welcomes with open arms anyone who has an interest in knowing more about thyroid disease and willing to share it with others. Call us, email us or talk to a board member you may know and we'll be glad to share with you our passions and why we, ourselves, are involved. You never know, you could be that extra link that will make a world of difference to the Thyroid Foundation of Canada or more especially other thyroid patients.

We would love to hear from you.

Mabel Miller  
President

Mes Salutations aux membres d'un océan à l'autre du Canada et ainsi d'autres pays où que vous soyez.

Quelle enthousiasmante AGA s'y était en juin 2016! C'était formidable de voir de nouveaux visages qui veulent se joindre au Conseil national. Certains sont des nouveaux membres et certains sont des membres qui étaient déjà parmi nous. Nous avons maintenant plus de membres au Conseil que nous ne l'avons eu depuis longtemps, des membres qui peuvent contribuer au travail qui doit continuer.

Il ne fait aucun doute d'après les contacts que nous avons, les appels que nous recevons et des histoires que nous entendons, qu'il y a beaucoup à faire en ce qui s'agit la Sensibilisation et l'Éducation en ce qui concerne les différents types de maladies de la thyroïde. Plus d'entre vous qui s'impliquent, plus d'information peut se propager partout au Canada. Comme la maladie de la thyroïde est principalement une maladie génétique, le partage d'information peut bien bénéficier dès votre propre famille jusqu'à vos amis, même des collègues et au-delà de votre cercle. C'est parfois un trajet de bouche à oreille – le message continue à se transmettre. Voilà ce que nous devons y faire.

C'est intéressant de voir surgir récemment des nouveaux développements et des nouvelles informations grâce à la recherche et à la science sur les conditions de la thyroïde. Dans ce bulletin, vous verrez certains de ces articles pour votre renseignement au sujet.

Le Conseil national accueille à bras ouverts tous ceux qui ont un intérêt à en savoir plus et à partager ses connaissances sur la maladie de la thyroïde. Appelez-nous, écrivez-nous ou parlez-en à un membre du conseil que peut-être vous en connaissez et nous serons heureux de partager avec vous nos passions et la raison dont nous y sommes impliqués. On ne sait jamais, vous bien pourriez être ce lien supplémentaire qui fera tout un monde de différence à la Fondation canadienne de la thyroïde ou plus particulièrement à autres patients de la thyroïde.

Nous aimerions beaucoup recevoir vos commentaires!

Mabel Miller  
Présidente

## Meet your New Board of Directors

**Mabel Miller**, President, is from Gander, NL. Retired from Federal Government with 22 years' service. Has extensive experience in management relating to client services, human resources and business administration. An avid volunteer and supporter with community organizations including church groups. Recipient, Governor General Caring Canadian Volunteer Award and The Queen's Golden Jubilee Award for volunteering. A member of TFC for 26 years and has held several Board positions as well as founding member (president) of TFC Gander chapter.

**Kristin Tresoar**, 1<sup>st</sup> Vice President, is from Winnipeg, MB. Kristin has a considerable amount of experience in media. Her background as a writer/ producer, field producer, writer/documentary director is a great asset to TFC. She has experience in writing a range of materials for different media platforms, including television, radio, print, and the web. Kristin has been a volunteer in various capacities with several organizations.

**Jane O'Heir**, 2<sup>nd</sup> Vice President, from Toronto, ON. She brings a great deal of experience in the Health delivery sector. Jane has extensive experience in Computer Science and IT related areas, Project Management and Consulting.

**Jeff Griffith**, Treasurer, is from Oakville, ON and brings to TFC a background in Governance, Executive Management and Communications including IT. He has been employed in the corporate world since 1989. Active in many community based projects.

**Gabriela Albaraccin**, Director, is from Ottawa, ON, a member of the Ottawa chapter and has been with the National board for over 3 years. She lends her expertise as a translator in the legal world and as a translator of materials and correspondence for TFC.

**Kim McNally**, Director, is from Kingston, ON. She has extensive background in Administration communications, training in various disciplines, dealing with Acts and Policies and other related areas. Active Volunteer with various non-profits for over 20 years, including the Thyroid Foundation of Canada.

**Michael Miller**, Director, is from Richmond Hill, ON, a retired Chemical Engineer who has worked extensively in the pharmaceutical field including over 35 years in senior manufacturing management. In addition to English, Michael speaks French, Russian, Polish, and has a good understanding of other Slavic languages.

**Heather Neil**, Director, is from Winnipeg, MB. She is a Registered Massage Therapist with a special interest in effects our hormones play. Heather also has a background in office administration, customer service and the volunteer sector.

**Giulia Ruscillo**, Director, is from Toronto, ON. She brings experience in office management, including supporting management teams and departments, client and customer service. A strong communicator and has volunteered with a number of non-profit organizations.

**Frances Salvaggio**, Director, is from Toronto, ON. Frances has a professional background in the field of law with experience in various aspects dealing with legal matters. As a lawyer, her knowledge is of great value when analyzing and referencing formal matters of the organization. She has been a volunteer in various capacities in her area.

Your new Board is busily working on new projects and improvements in spreading awareness and providing information to thyroid patients.

### Our Goals



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

### Nos objectifs

- **Sensibilisation** - Accroître l'intérêt du public envers les maladies thyroïdiennes et le sensibiliser davantage à ce problème.
- **Soutien** - Offrir un soutien moral aux personnes atteintes d'une maladie thyroïdienne et à leur famille.
- **Recherche** - Contribuer à recueillir des fonds pour la recherche sur les maladies thyroïdiennes.



## My TFC Journey



by Kim McNally

It is with great pleasure that I submit an article for this issue of Thyrobuletin. Having recently been elected as a member on the Board of Directors, I look forward to working with the dedicated volunteers who join me in carrying out the mission of TFC's Founder, our beloved Diana Metzler Abramsky.

My involvement with the Foundation began in 1987 when I first moved to Kingston. Having been diagnosed with thyroid cancer in 1981 (aged 15), I was seeking out any organizations or groups where I might find some more information on my own disease. Upon contacting the Foundation, I was introduced to a wonderful group of hard working and pleasant women, including Phyllis Mackey, Margaret Burdsall and Nathalie Gifford, who, along with their husbands, and other dedicated volunteers, worked tirelessly to bring public attention to thyroid disease in the Kingston area. I began attending meetings and before I knew it, I was volunteering with them, impressed by the many topics and speakers the Kingston Chapter was able to book, from endocrinologists to general surgeons among them.

I also had the honour of meeting Diana on a number of occasions and was invited to her home to meet with her personally. Her dedication to the Foundation and desire to be involved, even during the late stages of her own cancer diagnosis, appealed greatly to me and taught me the value of putting one's own misery aside to help others through theirs. Diana started the Thyroid Foundation of Canada in 1980 and brought it to National attention, deservedly receiving the Order of Canada in 1991 for her efforts.

Through my volunteer work, I was fortunate to meet renowned thyroidologist Dr. Robert Volpe, who answered patients' questions for the Thyrobuletin and who became part of my team of Doctors following the recurrence of my thyroid cancer in 1995. I travelled many times to see him in Toronto and upon his passing, submitted an article for the Thyrobuletin describing his stewardship in the world of thyroid disease and how much he helped me. I also had the pleasure of meeting Dr. Irving Rosen, who also answered patient questions, submitted articles for the Thyrobuletin and attended many meetings for the Foundation. Like many involved with the Foundation, these physicians saw the value in what we were doing, providing public education and information to anyone suffering from thyroid disease and were always willing to give of their time and expertise.

I am excited and eager to work with the newly elected Board in continuing the vision of the Thyroid Foundation of Canada. I believe I speak for all, when I say we remain dedicated to upholding those values Diana held dear, which include providing a place where people can seek assistance and get the help they require for thyroid disease. I wish to continue this spirit of charity for her hard work and look forward to where this new journey will take us.



Left: Kim with her Mom, Jean McNally

Cover photo: Kim with brother and sisters (from left) Jeannette Kenny, Sean McNally, and Jennifer McNally

### ANNOUNCEMENT – MEMBERSHIP FEE INCREASE IS COMING

With increasing costs it is becoming harder to deliver the programs and services we offer.

The Thyroid Foundation of Canada has not increased fees since 2004. We will provide more communication regarding changes to rates and new options in the months ahead. **RENEW NOW** to avoid the rate increases.

## Hypothyroidism symptoms linger despite medication use, normal blood tests



About 15 percent of the 10-12 million people in the U.S. with hypothyroidism, or an underactive thyroid, continue to feel sick despite following the standard of care recommended by the American Thyroid Association. Physicians routinely prescribe levothyroxine, a synthetic thyroid hormone, adjusting the dose until blood levels of thyroid-stimulating hormone (TSH) stabilize.

Despite normal TSH tests, these patients still have many nagging symptoms of hypothyroidism. "Patients complain of being depressed, slow and having a foggy mind," said Rush's Antonio C. Bianco, MD, PhD, an immediate past president of the American Thyroid Association that is professor of medicine at Rush and an expert on thyroid disorders. "They have difficulty losing weight. They complain of feeling sluggish and have less energy. Yet we doctors keep telling them, 'I'm giving you the right amount of medication and your TSH is normal. You should feel fine.'"

New research gives these patients - who often feel dismissed and forgotten - evidence that their persistent symptoms are not just in their heads.

Research conducted by Bianco and other Rush colleagues published Oct. 6 in the *Journal of Clinical Endocrinology and Metabolism* found that individuals on levothyroxine who had normal TSH levels were significantly more likely to be taking antidepressants than peers with normal thyroid function. The individuals taking thyroid medication were also less physically active, suggesting lower energy levels. They weighed about 10 pounds more than peers of the same height even though they consumed fewer calories, after adjustments for body weight. Plus, they were more likely to be using beta blockers, a drug frequently prescribed to lower blood pressure, and statins that reduce cholesterol levels.

"These findings correlate with what patients have been telling us," Bianco said. "This study documents for the first time, in an unbiased fashion, that patients on levothyroxine feel worse and are much less active than controls, exhibiting objective cardiometabolic abnormalities despite having normal TSH levels."

### The Current Treatment Approach

Women are most likely to suffer from hypothyroidism, which occurs when the thyroid gland in the neck stops producing enough hormones, most commonly due to an autoimmune disorder, according to Bianco. Hypothyroidism also develops when the thyroid is surgically removed (for example, due to cancer or benign nodules).

One of the thyroid's primary jobs is to regulate metabolism, which affects almost every organ and function in the body. For example, when thyroid hormones are low, as in hypothyroidism, the heart rate slows and the intestines process food at a reduced speed, causing constipation. The thyroid also affects the brain. "Your brain turns off," Bianco said. "Patients are tired, sleepy and might experience feelings of depression. If not treated, might slow down dramatically and slowly go into a sleep state, and eventually into coma."

There are two types of thyroid hormones: triiodothyronine (T3) and thyroxine (T4). Until the 1970s, patients with hypothyroidism were given pills containing both T3 and T4, which were made from desiccated, or desiccated, thyroid glands from cows and pigs.

But things changed after scientists made two seminal discoveries. One is that the thyroid mostly produces T4, which turns into T3 as it travels through the body. "The important thing to understand is that T4 is not the active hormone," Bianco said. "T4 must be converted to T3 by our bodies with an enzyme called deiodinase."

This finding led to the widespread treatment of hypothyroidism with levothyroxine monotherapy, which is the pharmaceutical grade of T4. As Bianco explained: "The medical community reasoned, 'Hypothyroid patients should be given only T4 as opposed to giving desiccated thyroid with both T3 and T4. Then the body, in its wisdom, will make enough T3.' This would avoid the potential side effects of giving straight active thyroid hormone T3."

The second discovery involved TSH, which is a hormone produced by the pituitary gland, a small organ at the base of the brain. Scientists determined that the pituitary and thyroid glands work together to ensure the body has enough T4 to turn into T3. When T4 levels are low as in hypothyroidism, the pituitary gland secretes TSH into the blood stream, stimulating the thyroid to produce more T4. A high TSH level in the blood is how physicians diagnose hypothyroidism, and they adjust up the dose of T4 (or the drug levothyroxine) until TSH levels are back in the normal range. "That is how patients are generally treated and monitored today for hypothyroidism," Bianco said. "While the therapeutic goal is to make patients feel better, symptoms alone are not utilized for judging adequacy of treatment. Blood TSH levels are. In other words, the dose of levothyroxine is adjusted based on the TSH levels and not whether or not the patient feels better."

### A Changing Paradigm

Because the majority of patients with hypothyroidism do well on levothyroxine monotherapy, which is considered a safe medication, the medical community has considered the treatment approach a success. However, in recent years, patient advocacy groups have helped draw attention to the plight of hypothyroid patients who feel sick despite taking levothyroxine and having normal TSH levels.

Because he and his colleagues specialize in thyroid disorders, Bianco tends to see a lot of these patients. "What they're looking for is someone to believe what they're saying," he said. "When I say, 'I understand and I believe you,' many of my patients start crying. These patients have been suffering and physicians have been dismissing them."

To learn more about why some patients were not feeling well in a completely objective, unbiased fashion, Rush researchers turned to a large publicly available survey, called the U.S. National Health and Nutrition Examination Survey (NHANES). More than 10,000 people participate in NHANES, a program of studies designed to assess the health and nutritional status of adults and children in the United States. The survey is unique in that it combines interviews and physical examinations.

*Continued on page 6*



Continued from p. 5

From that database, the Rush researchers identified 469 adults who were taking levothyroxine monotherapy and compared them to 469 individuals who were not on levothyroxine. Both groups were matched for age, sex, race, and serum TSH levels.

"We looked to see how 52 clinical measures differed between the two groups. Individuals taking levothyroxine weighed significantly more and moved less, they were also more likely to take antidepressants than those who were in the control group," said Sarah Peterson, PhD, first author of the study and registered dietitian at Rush University Medical Center.

Other findings included a significantly higher use of statins and beta blockers in the levothyroxine group, presumably for high cholesterol and high blood pressure.

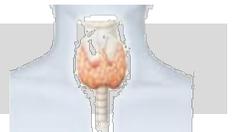
Rush University Medical Center. "Hypothyroidism symptoms linger despite medication use, normal blood tests." ScienceDaily, 12 October 2016. <http://www.sciencedaily.com/releases/2016/10/161012132038.htm>

**A Revised Dialogue**

Hypothyroid patients who continue to have symptoms on levothyroxine monotherapy might talk to their physician about trying combination therapy, or a pill that contains both T3 and T4. Trials of combination therapy are supported by the American Thyroid Association, but clinical studies are mixed on whether this approach works, Bianco said. Subjectively, some patients report feeling better and others don't.

Better medications are needed to treat hypothyroidism, Bianco believes. Until that day, he urges physicians to change how they talk about hypothyroidism treatment with patients. "Doctors should be telling their patients, 'I'm going to normalize your TSH, but you're going to be at a higher risk for gaining weight, experiencing depression and fatigue. It is also more likely that your cholesterol will go up.' That's what we should be telling patients, based on our study. This conversation is particularly important for any patient that is considering surgical removal of the thyroid gland."

**Canadian doctors first to implant cancer patients' thyroids in their arms**



Canadian doctors have pioneered an unusual way of protecting a cancer patient's thyroid from harmful radiation treatments, by removing the gland and implanting it in the arm.

In a world first, doctors in Alberta performed the thyroid transfers in 10 patients with head and neck cancers, which usually involve radiation treatments. While radiation kills off cancer cells, it can also damage surrounding tissue and the thyroid, an important endocrine gland that controls

metabolism and other body functions.

The results of the thyroid transfers were published in the International Journal of Radiation Oncology. [http://www.redjournal.org/article/S0360-3016\(16\)30107-9/abstract](http://www.redjournal.org/article/S0360-3016(16)30107-9/abstract)

This article can be viewed in full at: [www.ctvnews.ca/canadian-doctors-first-to-implant-cancer-patients-thyroids-in-their-arms-1.3049790](http://www.ctvnews.ca/canadian-doctors-first-to-implant-cancer-patients-thyroids-in-their-arms-1.3049790)

**Thyroid Foundation of Canada, Annual General Meeting 2016**

The 36th Annual General Meeting took place on June 11, 2016 at Four Points Sheraton Toronto Airport Mississauga ON. President Donna Miniely welcomed everyone including a lot of new faces that had not attended before as well as members who have attended for many years. It was great to see so much interest in being part of the National Board and very heartwarming to those who have been around for quite some time.

The Nominating Committee reported receiving enquiries from some with lots of related expertise. Eight new nominees were elected to the board resulting in a total of 12 board members. (Two since have not been able to continue.) There's lots of opportunity for all to get involved and help with the various tasks, programs and services. We look forward to a very successful year.

Following this a Board Development Workshop was conducted by Paulette Vinette, a Strategic Consultant to non-profits from

"Solutions Studio Inc." This was to be beneficial especially to new board members as well as current members. It helped set the basis for how TFC will function in the coming year and beyond. The weekend ended with everyone feeling very optimistic with carrying out and enhancing the programs and services for patients and families concerned with thyroid disease. We hope everyone will continue to support TFC so we can acquire the necessary resources needed.



From left: Katherine Keen, Admin Asst; Joan DeVille, K-W Chapter; Mabel Miller, incoming Ntl President; Donna Miniely, outgoing Ntl President



Cassandra Howarth, K-W Chapter; Michael Miller National Board Member

News

**Another successful Education Meeting for Kitchener-Waterloo chapter**

The K-W chapter had a really great meeting on October 27 with over 80 people attending. Dr. Nadira Husein, Endocrinologist from the K-W Area for 17 years, spoke on Autoimmunity and Thyroid Diseases. Education chair, Joan De Ville says, "Dr. Husein's presentation was excellent and we learned information that we had not heard before". Many questions from the attendees were answered. The Education Table was very busy with new members being signed up.

The National Board is very pleased we can offer such a service to thyroid patients. K-W has had great success with Education meetings, however it doesn't come without a lot of work and dedication of the chapter. K-W chapter is a great example of what we can do all across this country of ours, Canada. Thank you Kitchener-Waterloo.



**K-W Chapter volunteers:**  
L-R Kathy Pearce, Membership;  
Donna Kent, Education; Derek  
DeVille, Education; Cassandra  
Howarth, President; Dr. Nadira  
Husein, Endocrinologist



L-R Julie Piatek, Kitchener Public  
Library, Cassandra Howarth,  
Dr. Nadira Husein, Joan DeVille

**Kim McNally from Kingston looking to bringing back Education Meetings to the area**



L-R Cassandra Howarth, Joan DeVille,  
K-W Chapter; Kim McNally, Ntl Board

Recently Kim McNally from Kingston, and a member of the National board, was in Kitchener, ON and was able to take some time to meet up with Cassandra Howarth, President of Kitchener-Waterloo and Joan De Ville, Education Chair.

Kim recalls "One of the things I enjoyed most about the Kingston Chapter of the TFC were the public education meetings we held. When I met Cassandra at the AGM this year she mentioned that the Kitchener-Waterloo Chapter still hold approximately two meetings a year and they are quite successful. As I am now on the National Board (TFC) I would like to bring these meetings back to the Kingston area as I feel there is a need for this kind of information and they were always well attended in the past. We have a number of physicians who have been willing to give their time to these forums, and I hope that can be repeated". Kim further states, "I met with Cassandra and her mom Joan over the weekend and they gave me information on how they organize and plan meetings.

"I am hopeful we can do the same here in Kingston in getting our public education meetings up and running again and on that note, would ask that if anyone is interested in such an endeavor, please contact the foundation office and ask to be put in contact with me for follow-up. **I am seeking volunteers willing to assist with these meetings in the Kingston area.**" 1-800-267-8822 or email [info@thyroid.ca](mailto:info@thyroid.ca).

*Wishing you and your families the very best for the Holidays!*



**CANADA 150**



In honour of Canada's 150<sup>th</sup> Anniversary, this year's **Annual General Meeting** will be held in Ottawa, on May 6<sup>th</sup>, 2016, hosted by TFC's Ottawa Chapter.



It's our  
6<sup>th</sup> annual campaign  
**Light a Tree for Thyroid!**



Dear Members,

The Thyroid Foundation of Canada Board of Directors thanks you for your kind contributions to the **Light a Tree for Thyroid** campaign in the past.

Your generosity helps with .....

- Delivering programs
- Providing up to date information on the various types of thyroid diseases
- Upgrading our website in order to reach more thyroid patients
- Reviewing and printing our patient Health Guides with the latest medical information
- Reaching those in remote areas where the internet is not so accessible
- Compiling and printing our newsletter **Thyrobuletin**

Please help us to continue our work by .....

- Renewing your membership
- Giving a gift membership, and
- Making a donation

Use the form below or go to **www.thyroid.ca** to make your online secure payment by credit card.

Every \$25.00 donation puts a light on our Thyroid Tree and helps us continue our work for thyroid patients. Go to **www.thyroid.ca** to see how our Tree is lighting up!

Please be generous with your contribution.

Note: Making a donation now will give you a tax receipt before Dec. 31, 2016



Thyroid Foundation of Canada  
La Fondation canadienne de la Thyroïde

## Membership and Donation form

Light a  for Thyroid

Name:		Address:			
Telephone:		Email:			
<b>Membership:</b>	One Year	<input type="checkbox"/> Regular \$25	<input type="checkbox"/> Senior \$20	<input type="checkbox"/> Student \$20	<input type="checkbox"/> Family \$30
	Two Year	<input type="checkbox"/> Regular \$40	<input type="checkbox"/> Senior \$30	<input type="checkbox"/> Student \$30	<input type="checkbox"/> Family \$50
\$	<b>Membership</b>	<i>Members receive Thyrobuletin</i>			
\$	<b>Donation</b> 	<i>All donations support the work of the Thyroid Foundation of Canada</i>			
\$	<b>TOTAL PAYMENT</b>				
<input type="checkbox"/>	Visa	<input type="checkbox"/>	MasterCard	<input type="checkbox"/>	Cheque <i>(payable to: <b>Thyroid Foundation of Canada</b>)</i>
Visa/MasterCard No.:			Expiry Date:		
Name on Card:			Receipt: <input type="checkbox"/> By regular mail <input type="checkbox"/> By email		

*Thank you for your support!*



*Wishing you the best for the Holidays!*