



Our Stories

Research

Activities

TFC Thyroid **Research Program**



Hypothyroid Patient Project

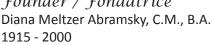
E-MPATHY study E-Mode Patient self-Assessment of THYroid therapy



Thyroid Foundation of Canada La Fondation canadienne de la Thyroïde



Founder / Fondatrice



La Fondation canadienne de la Thyroïde

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The Voice and Face of Thyroid Health in Canada

La voix et le visage de la santé thyroïdienne au Canada

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Thank You Mabel!

We would like to thank Mabel Miller for her years of service with the Thyroid Foundation of Canada and for her work as Thyrobulletin Editor over the past few years. She retired after our last AGM but continues to assist the board as Past President.

Mabel was President in 2011-2013 and also in 2016-2017, has also worked on the board in different capacities and has been around TFC for about 30 years. She has an excellent knowledge



Mabel Miller

of the history of the foundation and enjoys talking about past members who have contributed to its success.

She is deeply supportive of the foundation and always strives to ensure that it continues on with its important work for years to come!



Autumn 2020

MESSAGE FROM THE PRESIDENT Message du président

Dear Members,

This year, the Thyroid Foundation of Canada (TFC) celebrated its 40th anniversary. The pandemic has not had a big effect on the running of TFC, since we have been operating virtually for a number of years. However, it did put a delay on our Annual General Meeting which is usually held in June. We held our first virtual AGM on November 7th!

Thyroid Patient Services

Over the past year and a half, we continued to provide up-to-date news and articles on our new website and our Thyrobulletin newsletter. We entered into a co-sponsorship agreement with Mylan pharmaceutical, for the development of videos on hypothyroidism which were published on our website last winter. Our Help Line team continued to provide information assistance and moral support for members through our 1-800 toll free line and via email. Finally, to further our research objectives, we signed the research agreement with Canadian Society of Endocrinology and Metabolism (CSEM) to help us support thyroid research in Canada over the coming years! For thyroid awareness, we sent out a press release for June is Thyroid Month.

Internal Operations

We invested a large amount of our research funds in GICs. In our last fiscal year, ending march 2020, we had a net income of \$8,326. We separated our operational funds from our restricted research funds by placing them in separate bank accounts. We changed our IT service provider to improve our website support. For fundraising, we continued with our annual Light a Tree for Thyroid initiative originally developed by Mabel Miller and received corporate donations and several thyroid bequests.

Next Period

Plans for the next period are to hold a pilot virtual public education session on thyroid disease in February. If all goes well, we will establish several public education sessions next year. We would like to activate two new website services that are part of the "Just for members" section: Member's Forum and the Medical Advisory service. The member's Forum service enables discussions among TFC members. This will also facilitate the development a Buddy System for members in need. We would also like to increase the size of our board as we are currently operating at a minimal level. To volunteer or for assistance with a thyroid issue, please contact us at 1-800-267-8822 or by email at: info@thyroid.ca.

Wishing all of you a safe and Happy Holiday season! Laz Bouros, President Chers membres,



Cette année, la Fondation canadienne de la thyroïde (TFC) a célébré son 40e anniversaire. La pandémie n'a pas eu un grand effet sur le fonctionnement de TFC, puisque nous opérons pratiquement depuis plusieurs années. Cependant, cela a retardé notre assemblée générale annuelle qui se tient habituellement en juin. Nous avons tenu notre première AGA virtuelle le 07 novembre!

Services aux patients thyroïdiens

Au cours de la dernière année et demie, nous avons continué à fournir des nouvelles et des articles à jour sur notre nouveau site Web et notre bulletin d'information Thyrobulletin. Nous avons conclu un accord de co-parrainage avec Mylan Pharmaceutical, pour le développement de vidéos sur l'hypothyroïdie qui ont été publiées sur notre site Internet l'hiver dernier. Notre équipe d'assistance téléphonique a continué à fournir une assistance en matière d'information et un soutien moral aux membres par le biais de notre ligne sans frais 1-800 et par courriel. Enfin, pour poursuivre nos objectifs de recherche, nous avons signé un accord de recherche avec la Société canadienne d'endocrinologie et de métabolisme (CSEM) pour nous aider à soutenir la recherche sur la thyroïde au Canada au cours des prochaines années! Pour la sensibilisation à la thyroïde, nous avons envoyé un communiqué de presse pour juin est le mois de la thyroïde.

Opérations internes

Nous avons investi une grande partie de nos fonds de recherche dans des CPG. Au cours de notre dernier exercice, se terminant en mars 2020, nous avions un revenu net de 8 326 \$. Nous avons séparé nos fonds opérationnels de nos fonds de recherche affectés en les plaçant sur des comptes bancaires séparés. Nous avons changé de fournisseur de services informatiques pour améliorer le support de notre site Web. Pour la collecte de fonds, nous avons poursuivi notre initiative annuelle Light a Tree développée à l'origine par Mabel Miller et avons reçu des dons d'entreprises et plusieurs legs thyroïdiens.

Prochaine période

Les plans pour la prochaine période sont de tenir une session pilote virtuelle d'éducation publique sur les maladies thyroïdiennes en février. Si tout va bien, nous mettrons en place plusieurs séances de sensibilisation du public l'année prochaine. Nous souhaitons activer deux nouveaux services de site Web qui font partie de la section «Juste pour les membres»: le forum des membres et le service de conseil médical. Le service Forum des membres permet des discussions entre les membres du TFC. Cela facilitera également le développement d'un système de jumelage pour les membres dans le besoin. Nous aimerions également augmenter la taille de notre conseil car nous fonctionnons actuellement à un niveau minimal. Pour faire du bénévolat ou pour obtenir de l'aide pour un problème de thyroïde, veuillez nous contacter au 1-800-267-8822 ou par Courriel à : info@thyroid.ca.

Je vous souhaite à tous un temps des fêtes sûr et heureux! Laz Bouros, Président

Autumn 2020

OUR 40TH ANNIVERSARY VIRTUAL AGM



GREETINGS AND PRESENTATIONS



Dr. Deric Morrison, TFC Medical Advisor, Endocrinologist, St. Joseph's Health Centre, London ON



Inika Anderson Executive Director, Canadian Society of Endocrinology & Metabolism



"Tall Oaks from Little Acorns Grow"

by Diana Hains Meltzer Abramsky

. Q.C



"... a wonderful presentation was made by Mabel Miller on the history of the Foundation using photographs from our Spring 2020 Thyrobulletin."

BOARD OF DIRECTORS 2020-2021

President	Laz Bouros	Ottawa ON
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Member-at-Large	Ashley D'Alessandra	Tecumseh ON
Member-at-Large	Parisa Zareapour	Toronto ON

2020 TFC AGM HIGHLIGHTS

This year, we celebrated our 40th anniversary with our first virtual AGM. Conducting our AGM using Zoom brought on additional complexities for us. We performed some initial testing on Zoom and discussed a number of requirements for achieving a successful AGM. We were very fortunate to have the assistance of member, Tatyana Medvedyeva, who took on the role of "producer". This meant that she was looking after the technical aspects of Zoom throughout the AGM.

One of the advantages of using virtual technology for connecting people is that you can get more people attending the AGM. With a relatively short lead time, we were able to get 24 people registering for the event. Some of the faces shown in the picture above included board members Laz Bouros, Kim Mcnally, Mabel Miller, Tracy Hey, Parisa Zareapour, Katherine Keen, our administrator and Lauri Martin, our Help Line volunteer. In attendance were also Cassandra Howarth, President of the Kitchener-Waterloo Chapter, Caroline Goodfellow, President of the Ottawa Chapter, as well as Joan and Derek Deville also from the Kitchener-Waterloo Chapter and Donna Miniely, Past National President. Board members presented their reports. The agenda began with a welcome message from Laz Bouros, the President. He introduced Tatyana Medvedyeva who kindly volunteered to act as Zoom "producer" for the session and provided participants with instructions on the use of Zoom features. The new agenda and meetings from the last AGM were approved. Board members then proceeded to give their reports. This was followed by the election of directors. The new board members elected included: Laz Bouros, President, Kim McNally, Vice-President, Tracy Hey, Parisa Zareapour, Tatyana Medvedyeva and Ashley D'Alessandro. Other positions to be determined by the board.

We received video presentations from Dr. Morrison, our Medical Advisor and Inika Anderson, Executive Director of CSEM. Unfortunately, we had difficulties presenting these

on Zoom and resorted to emailing the downloadable video links to all attendees later on. Finally, a wonderful presentation was made by Mabel Miller on the history of the Foundation using photographs from our Spring 2020 Thyrobulletin. For our first virtual AGM, it went rather well!



Autumn 2020

E-MPATHY STUDY

The Thyroid Foundation of Canada (TFC) has been asked to share information about a study that's being conducted by Thyroid Federation International (TFI) with its own TFC members and thyroid patients across Canada.

TFI, a global network of patient support organisations teamed up with four international thyroid experts to conduct research that will help us to understand patient experiences of treatment and care. This E-MPATHY (**E-M**ode **P**atient self-**A**ssessment of **THY**roid therapy) study is being overseen by Picker Institute Europe (Picker), who are an independent healthcare research charity (www. picker.org). Funding for the project is provided by Institut Bio-Chimique SA (IBSA). They are reaching out to patients diagnosed with hypothyroidism, asking them to complete a questionnaire.

They have developed and tested an online patient experience questionnaire that is now being used to gather feedback from patients receiving care for hypothyroidism about their experiences of care and treatment. The survey also asks about quality of life, personality and some demographic questions such as age, household status and gender. Participants must have a diagnosis of hypothyroidism, and be at least 18 years of age. Participation in this research is entirely voluntary and all information provided will be kept entirely confidential.

The findings from the survey will help to better understand patient experiences of treatment and care, and answer key research questions about:

- Satisfaction levels with treatment for hypothyroidism;
- The perceived treatment barriers and enablers for successful treatment;
- Unmet treatment needs;

• Whether or not there are any associations that can be drawn between different factors (demographic/comorbidities/personality) and treatment satisfaction.

The survey portion of the study will run from November 2020 to January 2021. The study should be ready for publication by mid-2021 and we will be able to segregate the results by country.

For additional information about the study and to learn how to participate, please see <u>e-mpathy-study</u>.



THYROID RESEARCH UPDATE

BY LAZ BOUROS

TFC Signs Research Agreement!

The Thyroid Foundation of Canada (TFC) signed an agreement with the Canadian Society of Endocrinology and Metabolism (CSEM) last October for the management of our thyroid research grants. CSEM is a professional organization for the 600 endocrinologists in Canada. They already have an Awards and Grants Committee in place and agreed to let TFC use it to manage our TFC grants.

The development of this agreement began about a year ago and required considerable effort to complete for both organizations. We were very fortunate to have our legal advisors, Gowling WLG, support us with this agreement over the past year. TFC grants of \$50,000 per year will be awarded to a Canadian researcher who is focused exclusively on thyroid disease. The first award will be presented to the selected recipient at the next CSEM Professional Conference in the fall of 2021. There are many advantages for partnering with CSEM:

- CSEM has an Awards Committee, procedures, and endocrinologists that are knowledgeable in the research area;
- They regularly send out requests for proposals to university medical schools and hospitals for other grants that they manage;

• Dr. Morrison, our Medical Advisor, and another board member will sit on the CSEM Awards Committee and participate in the award selection process;

• TFC grants will focus on thyroid research that impact patient care;

• Thyroid research results are vetted by CSEM (research process, etc.) and provide greater legitimacy for the thyroid research.

Part of TFC's mission is to raise funds to support thyroid research. In recent years, TFC has not been in a position to promote thyroid research in Canada. This two-year renewable agreement with CSEM is a signal to the Canadian research community that TFC is serious about promoting thyroid research and that we have the funds to support thyroid research for many years to come!



Autumn 2020

ASK THE DOCTOR

Hello,

I'm hoping to be directed to literature or info sheets that might help my current situation. I understand the Foundation cannot provide medical advice, but I'm having trouble finding info for my specific condition.

I had a full thyroidectomy at the age of 13 and of course have been on thyroid replacement since then. Now at the age of 44 I'm currently, rather suddenly in the past months, experiencing a very high TSH level and starting the road of adjusting meds to see if I'm responsive to this sudden change. I thought I might have had an interaction with a new supplement, but after a 4–5 week bloodwork

follow-up after stopping the supplement, my TSH has budged only slightly from 9 to 8.85. This is highly irregular for me.

I'm wondering a few things:

Is there specific information available for understanding how the body is affected by long-term thyroidectomy?
Is there specific information regarding mid-life hormonal changes in women and how that might affect thyroxine absorption and requirement, particularly in someone who has had a thyroidectomy?

I find a lot of information on hypothyroidism and decreased function in mid-life, but because I don't have a thyroid, none of that quite applies. Any help would be greatly appreciated as I am currently working only with a GP and am not yet at the stage for an endocrinologist referral.

Daniella, Toronto ON

Response from the Medical Advisor

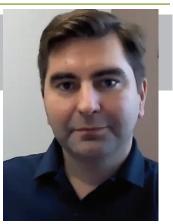
The approach of the Family Doctor to increase the dose to normalize the TSH is appropriate. Levothyroxine requirements can change due to changes in absorption (usually eating at the same time as taking, or taking other meds/vitamins at the same time as levothyroxine), changes in weight (weight gain may increase requirement, loss decrease), changes in estrogen levels (more estrogen, like oral contraceptive pills and pregnancy, increase requirements; less estrogen, like menopause, decreases requirements. The timing of development of hypothyroidism/thyroidectomy is probably not relevant.

The next section is of very rare situations and should only be considered if increasing the dose or identifying a cause of impaired absorption does not solve the issue, or if the FT4 goes above the normal range but TSH remains elevated.

Rarely (outside of impairing absorption) drug interactions can affect the metabolism of thyroid hormones. TSH levels can be falsely elevated by interfering substances in a patient's blood, e.g. heterophile antibodies, rheumatoid factor or the presence of inactive macro TSH.

Deric Morrison, MD FRCPC, ECNU, Endocrinologist, Assistant Professor, Division of Endocrinology, Dept. of Medicine, University of Western Ontario, London, Ontario

Do you have a medical question that might be helpful to other thyroid patients? Send it to <u>info@thyroid.ca</u> - or Thyroid Foundation of Canada, P.O. Box 298, Bath ON KOH 1GO



Dr. Deric Morrison

MY JOURNEY WITH HASHIMOTO'S

I was 12 years old when my mom took me to the doctor and said, 'I don't really know what's going on, but I think she's depressed.' I was shocked to hear her say that, but deep down I knew she was right. I sat in the examination room and cried while they discussed the possibilities of why a 12 year old girl was so out of sorts.

I took the time to reflect on where my health may have taken a turn.

Was it when I started to need a blanket to sit outside in the dead of summer or when it started hurting just getting out of bed? I never put much thought into why I felt sad when my life was so good or why I continued to gain weight when I tried so hard to be healthy. I felt like I was in a daze all of the time, like I wasn't a part of my own life. Not present. Not fully there. Everyday tasks became increasingly difficult. I continued to have difficulties in school and I couldn't concentrate on anything in front of me. I spent the majority of my time rereading questions over and over again yet nothing was getting absorbed. Most of my nights were spent having extremely hot baths because it was the only way to warm my body back. I was often so cold that it would hurt me to the core and there was nothing to help. I remember a time when I was in the bathtub trying to get my body temperature to a normal range. I was in there for hours, up to my neck in scorching hot water, just too afraid to get out because of the chills that would creep in after. I was too weak and exhausted and the only thing I could do was lie there submerged. The next thing I knew my mom was picking me up out of the tub. Perhaps that is the moment my mom started questioning my health.

As I snapped back to reality, my doctor was filling out a requisition for blood work. A full panel focusing on my thyroid levels. At this point in my life, it wasn't often that I would need to get blood work done. Little did I know this would be a very common occurrence in my life. A few days went by and my doctor called with my results. I was suffering with Hashimoto's thyroiditis (the autoimmune form of hypothyroidism.)

This diagnosis scared me. I didn't know anything about the thyroid or how important of an organ it was nor did I realise how greatly an underactive thyroid could affect your overall health. I was prescribed levothyroxine and was told I would have to take it for the rest of my life. One tiny pill for the rest of my life. The task seemed easy enough, but I was young and ignorant to the annoyance that would come from it –



remembering my pill bottle when I slept over at a friend's house or remembering to take it at the same time everyday. I hardly remembered my homework, let alone a pill.

As a young girl, I didn't spend too much time thinking about it. I didn't educate myself on the thyroid or any triggers that could worsen it. I didn't acknowledge the long term affects.

As life went on, continuing to take my medication, I got married in my 20's and decided to start a family. It didn't take long to realise that becoming pregnant would not be an easy feat for me. Three pregnancies ended in miscarriage and with that came mental health struggles. After tweaking my thyroid medication and receiving a progesterone supplement I became pregnant. After two successful pregnancies that went to full term, I realised how important it was to educate myself on my condition as it really could affect all aspects of my life.

Over the past few years I have really got to know my body. I know what works and what doesn't with diet and exercise. I've tried intense boot camps and yoga, elimination diets, carb cutting and everything in between. The result - I do what works for me and what feels best for my body. In my case, it's spinning, following a gluten free and sugar free diet, little caffeine consumption and having calm environment with minimal stress, just to name a few.

Everyone's experience with their thyroid condition is different and unique. You must find what works best for you in order to live a happy and healthy life.

Ashley D'Alessandro is a new member and TFC Board Member-at-Large

LOUISE'S STORY

I will be 67 in October. I've had a lot of accidents in my life but I remember most the one of 2004 - car accident, whiplash and 4 broken ribs on the left side.

From 2004 to 2008 my neck was swollen on each side and sometimes blue. My family doctor at the time attributed this to my accidents and a decomposing bone in my neck.

In 2008 I lost weight from 120 lbs to 79 in the space of two months. A doctor at the clinic where I worked saved me. He spoke with my family doctor and my file was referred to an endocrinologist.

In September 2009 I was given two radioactive pills. The technician at Lakeshore told me that I had been sick for several years. At the time I was told I would have health consequences, without specifying which ones, Graves' disease was never mentioned.

In November 2009 I insisted on a sleep apnea test. The endocrinologist called me crazy but my test results showed respiratory arrest 88 times in an hour.

In 2011 I saw a new doctor - ENT - for chronic rhinitis.

In 2015 I developed Bell's Palsy; the symptoms include sudden weakness in the facial muscles. I had physiotherapy to regain my facial muscles for a year and a half - 93% healed.

Since Graves' disease has imposed itself - chronic osteoarthritis, glaucoma, Type 2 diabetes, fluctuating hypertension, nervousness, shortness of breath, etc.

Between 2015 and 2020 I lost 4 teeth while eating eggs.

In 2019, I had foot problems and was treated for gout arthritis. I hate taking chemicals.

I had naturopathy treatments: boswellia for osteoarthritis, glyco X for blood sugar, and tilia cordata for supposed gout (in your documents it would be thyroid acropathy), dermopathy - I put silica on wounds that heal well.

(Continued on page 10)



L'HISTOIRE DE LOUISE

J'aurai 67 ans en octobre. J'ai eu beaucoup d'accidents dans ma vie mais je retiens le plus celui de 2004. Accident de voiture, whiplash et 4 côtes de cassées coté gauche.

De 2004 à 2008 mon cou était enflé chaque côté et bleu parfois. Mon médecin de famille à l'époque attribuait ce phénomène à mes accidents et un os qui se décompose au niveau du cou.

En 2008 je maigrissais de 120 lbs à 79 dans l'espace de deux mois. Un médecin de la clinique ou je travaillais m'a sauvé. Il a parlé avec mon médecin de famille et mon dossier a été transmis à un endocrinologue.

En septembre 2009, j'ai reçu deux comprimés radioactifs. Le techinicien au Lakeshore m'a dit que j'étais malade depuis plusieurs années. A l'époque on m'a dit que j'aurais des séquelles sans préciser lesquelles Maladie de Graves n'a pas été invoquée.

En novembre 2009, j'ai insisté pour un test d'apnée du sommeil. L'endocrinologue m'a traité de fou, mais les résultats de mes tests ont montré un arrêt respiratoire 88 fois en une heure.

En 2011, je suis allé voir un nouveau médecin - ORL - pour la rhinite chronique.



En 2015, j'ai développé la paralysie de Bell; les symptômes comprennent une faiblesse soudaine des muscles faciaux. J'ai eu de la physiothérapie pour retrouver mes muscles faciaux pendant un an et demi - 93% guéri.

Depuis la maladie de Graves s'est imposée arthrose chronique - glaucome, diabete type 2, hypertension qui fluctue, nervosité, souffle court, etc..

Entre 2015 et 2020 j'ai perdu 4 dents en mangeant des oeufs.

En 2019j'ai eu problèmes aux pieds - suis soignée pour la goutte arthrite je déteste les produits chimiques.

J'ai eu des traitements de naturopathie: boswellia pour l'arthrose, glyco X pour glycémie, et tilia cordata pour la supposée goutte (dans vos documents il s'agirait d'acropathie thyroidienne) dermopathie - je mets de la silice sur les plaies qui guérissent bien.

(Suite à la page 10)





(Suite de la page 9)

I don't accept the power of Graves' disease over me. We do not die of it, but there is suffering.

II will continue reading, I will also include the Paleo diet although I have cookbooks for healthy thyroid function and also homemade vegetable juices.

Louise Duval is a new member of TFC. She lives in Laval QC.



J'accepte pas le pouvoir de la maladie de Graves sur moi. On n'en meurt pas, mais il y a des souffrances.

Je vais continuer à lire, je vais aussi inclure la diète Paleo même si j'ai des livres de recettes pour le bon fonctionnement de la thyroide et aussi des jus de légumes maison.

Louise Duval est un nouveau membre de FCT. Elle habite à Laval QC.

THYROID MONTHS

There are many types of Thyroid Disease. Each month we are featuring a different Thyroid topic on our website. Below are the topics coming up in the next months.

November	Thyroid Disease and Seniors	
December	Hyperthyroidism	
January	Thyroid Disease and Mental Health	
February	Graves' Eye Disease (Ophthalmopathy)	
March	Thyroiditis	
April	Thyroid Cancer	
Visit <i>thyroid.ca</i> each month to read our Thyriod Topics		

Is it time to renew your membership?

Use the membership form on page 12 or renew online at **thyroid.ca**/



QUILT FUNDRAISER, GANDER, NL - A LUCKY WINNER!



Thyroid Foundation of Canada Lottery

Gander, Newfoundland & Labrador group of Thyroid patients had planned on a fundraiser for TFC during the past year.

While they were able to finally get things moving the success of the event was dampened considerably by Covid 19.

Nevertheless all proceeds received from such projects are very much appreciated and will be used in the operation of TFC.

Thank you to Mabel and Fellow Quilters!

HAVE YOU GIVEN ANY THOUGHT TO LEAVING A BEQUEST TO TFC?

The Thyroid Foundation of Canada 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 provide 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. Learn more on our website at: **thyroid.ca/bequest**

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

Autumn 2020

Thyrobulletin



10th Annual Campaign

Light a **T**ree for **T**hyroid!

Every donation of **\$25** puts an ornament on the Tree and will help fund our programs including:

- Maintaining our Website thyroid.ca, which provides thyroid-related news and information
- Providing Resource Materials on Thyroid Disease to thyroid patients and medical facilities
- Managing our Toll-free Help Line
- Producing Thyrobulletin, TFC's official newsletter with news, patient stories and events
- Holding Public Information Meetings and Forums
- Awarding funds to carry out research on thyroid disease to improve the lives of thyroid patients

Please help support our thyroid programs

MEMBERSHIP AND DONATION FORM			
Name:	Telephone:		
Address:	Email Address:		
MEMBERSHIP LEVEL			
ONE YEAR:	TWO YEAR:		
□ Regular \$35 □ Senior \$30 □ Family \$45	□ Regular \$60 □ Senior \$50 □ Family \$65		
DONATION AMOUNT □ \$25 □ \$100 □ Other \$			
\$ Total Amount (All membership fees and donations are issued official tax receipts)			
PAYMENT METHOD			
□ Visa □ MasterCard □ Cheque (Payable to Thyroid Foundation of Canada)			
Visa / Mastercard No.:	Expiry Date: CVV No:		
Mail to: Thyroid Foundation of Canada, P.O. Box 298, Bath ON KOH 1G0			
Pay online, save postage and get your automatic tax receipt!			
Wishing you a safe and happy Holiday Season. Thank you for your support!			