

Thyrobulletin

Spring 2020



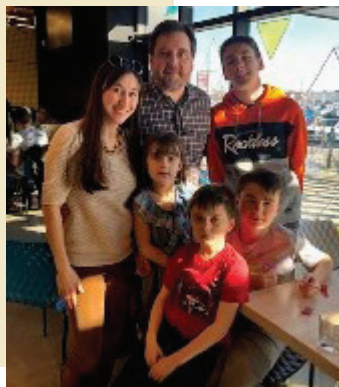
Looking Back - 40 Years

Behind the Scenes at TFC

Thyroid Hormone Replacement
for Hypothyroidism

Hyper to Hypo,
Susey's Story

A Graves' Disease/
Mental Health
Tragedy



TFC Thyroid Research Program

June is Thyroid Month in Canada!



Thyroid Foundation of Canada
La Fondation canadienne de la Thyroïde



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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2019-2020

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Thyroid Foundation of Canada
P.O. Box 298, Bath ON K0H 1G0

800.267.8822 info@thyroid.ca

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FROM THE EDITOR

Hello all readers,

"Circumstances alter cases" a quote I often heard used by my mother many years ago. While it's not heard much these days it certainly is relevant to how we live and what we do. This year the Thyroid Foundation of Canada celebrates its 40th Anniversary, a time to celebrate and recognize how the organization has positively impacted thousands of thyroid patients across this country and beyond. Sadly our plans for celebrations had to be postponed as we await what will happen with the necessity to restrict gatherings, travel, etc because of COVID 19.

Thyroid Foundation of Canada began all because one person, Diana Meltzer Abramsky, a thyroid patient from Kingston, ON saw a need to do something to help others with thyroid disease. Diana felt there was a need to develop a means whereby thyroid patients could be better informed on what was happening to them because of the thyroid malfunctioning. What resulted from this became much, much bigger than Diana ever imagined, I'm sure.

In 1980 Diana, along with the encouragement and support of her endocrinologist, Dr. Jack Wall embarked on bringing together others who had a thyroid condition and the desire to form a group to promote Education and Awareness on thyroid disease. This resulted in formation of thyroid patient groups and developing information articles written by professionals, endocrinologists that could be shared. This was followed by addressing the need for research which would help further understand the impact of the thyroid conditions on patients so affected.

Being able to obtain much desired information on thyroid conditions spread and soon chapters were formed from coast to coast with at least one chapter in each province. Today however information is more readily available through the internet, our website www.thyroid.ca and Facebook. The need for chapters diminished as the ability to gather in person to obtain information and listen to keynote speakers was no longer necessary. Nevertheless there's still lots of work to be done and we still maintain a National presence where patients can contact us with their concerns through 1-800-267-8822.

The Thyroid Foundation, the first organization of its kind in the world became recognized by other countries who saw a need for establishing similar groups. Today there are thyroid organizations all over the world all because of one individual taking the initiative to move in a positive direction. In 1995 those organizations came together in Toronto to form Thyroid Federation International. Diana was there to see the fruits of her Dream and so proud she was, so were TFC members attending (I am glad to say I was there).

While we may not be able to gather to celebrate this monumental occasion we will still recognize how the efforts of just one individual thyroid patient has positively impacted so many all over the world.

Mabel Miller
Editor



May your day begin
with a SMILE on your face,
a SONG in your heart,
and JOY in your soul!



MESSAGE FROM THE PRESIDENT MESSAGE DU PRÉSIDENT



Dear Members

On behalf of the TFC Board, I would like to wish everyone a safe passage through this difficult CORONA-19 virus period. The recent announcement from the British Thyroid Foundation indicates that the virus will not have any unusual impact for thyroid patients. The article states that "Thyroid disease is not known to be associated with increased risk of viral infections in general, nor is there an association between thyroid disease and severity of the viral infection." The complete article is available in the news section of our website.

Thyroid patients are urged to follow the established physical distancing and hygiene measures required for everyone. Medical services are considered essential and will continue to be provided by hospitals, clinics, medical labs, diagnostic centers, physicians' offices, pharmacies, etc. A sincere "thank you" goes out to our first responders who take on additional risk to provide us with these essential services. For those not wishing to venture outside, there's a variety of provincial telehealth services available as well as many private online telemedicine services.

Since TFC's work is already conducted in a virtual electronic environment, we have been fortunate not to have had to close offices and send people home as some other larger charities may have done. Some of our board members have had to deal with working from home and having to look after their kids, grand kids and relatives as well. Combined with the school closures, it has created additional demands on many. At our next board meeting, we will be considering rescheduling our June 13th Toronto AGM or having the meeting conducted via teleconference instead.

Please stay safe and follow the required measures for COVID-19. To volunteer or for assistance with a thyroid issue, please contact us at 1-800-267-8822 or by email at info@thyroid.ca.

Laz Bouros
President

Chers membres

Au nom du conseil d'administration du TFC, je souhaite à tous un bon passage dans cette période difficile du virus CORONA-19. L'annonce récente de la British Thyroid Foundation indique que le virus n'aura pas d'impact inhabituel pour les patients thyroïdiens. L'article indique que «la maladie thyroïdienne n'est pas connue pour être associée à un risque accru d'infections virales en général, et il n'y a pas non plus d'association entre la maladie thyroïdienne et la gravité de l'infection virale». L'article complet est disponible dans la section actualités de notre site Internet.

Les patients thyroïdiens sont invités à suivre les mesures d'hygiène physique et de distanciation établies requises pour tout le monde. Les services médicaux sont considérés comme essentiels et continueront d'être fournis par les hôpitaux, les cliniques, les laboratoires médicaux, les centres de diagnostic, les cabinets de médecins, les pharmacies, etc. Un sincère «merci» va à nos premiers intervenants qui prennent des risques supplémentaires pour nous fournir avec ces services essentiels. Pour ceux qui ne souhaitent pas s'aventurer à l'extérieur, il existe une variété de services de télésanté provinciaux ainsi que de nombreux services privés de télémédecine en ligne.

Étant donné que le travail de TFC est déjà mené dans un environnement électronique virtuel, nous avons eu la chance de ne pas avoir à fermer de bureaux et de renvoyer des gens à la maison, comme d'autres organisations caritatives plus importantes l'ont peut-être fait. Certains membres de notre conseil d'administration ont dû faire face à un travail à domicile et à s'occuper de leurs enfants, petits-enfants et parents également. Combiné aux fermetures d'écoles, il a créé des exigences supplémentaires pour beaucoup. Lors de notre prochaine réunion du conseil d'administration, nous envisagerons de reporter notre AGA du 13 juin à Toronto ou de faire tenir la réunion par téléconférence à la place.

Veuillez rester en sécurité et suivre les mesures requises pour COVID-19. Pour faire du bénévolat ou de l'aide pour un problème de thyroïde, veuillez nous contacter au 1-800-267-8822 ou par courriel à info@thyroid.ca.

Laz Bouros
Président



40 YEARS!
1980 - 2020

Brief history of Thyroid Foundation of Canada

“Tall Oaks from Little Acorns Grow”



by
**Diana Hains Meltzer
Abramsky**

need psychiatric evaluation” attitudes that were the usual experience of patients one met at thyroid clinics.

With encouragement from Dr. Jack Wall and W.W. Viner, Q.C., a public meeting was organized to discuss the merits of forming a thyroid organization, whose purpose would be to learn about and inform the public about the prevalence and nature of thyroid disorders. Informed patients would hopefully encourage their physicians to focus on the need to order thyroid function tests, sooner rather than later; to persuade their physicians to place thyroid gland investigation closer to the top, rather than at or near the bottom of the medical investigation totem pole.

Thus, in the summer of 1980, thyroid history was made in Kingston, Ontario, Canada. For the first time anywhere in the world, a public meeting was held, a committee was formed and on July 15, 1980 – a red letter day – the official founding of the Thyroid Foundation of Canada took place at Kingston City Hall where a plaque recording the event was unveiled in June 1996.

In chapters across Canada dedicated members of Thyroid Foundation of Canada accepted the challenge to end the

strange silence and the casual attitude that existed for centuries vis-a-vis thyroid disorders.

News of our existence spread across Canada by letters, word of mouth and numerous cross-country media reports. We were inundated with letters from despairing patients; – parents, children, and, yes, even from teachers, nurses and physicians including a Health Sciences physician in Paraguay who requested our thyroid information for his medical students’ educational programs. It was a veritable avalanche of requests.

From these letters it was quite obvious that my vision – my dream of a world-wide thyroid organization – was not far fetched. The information gap was not unique to Canada. It was a universal problem. Somehow hope and help had to be brought to people everywhere who were suffering from a malfunctioning thyroid gland. Today, Thyroid Federation International (TFI) is in a position to offer that help and that hope.

A sense of purpose and involvement is being shared by members of thyroid organizations being established around the world as well as via Thyroid Foundation of Canada’s educational material being made available on the World Wide Web.

*“How Far That Little Candle
Throws His Beams”*

Before the summer of 1980, information about thyroid disorders, at least, insofar as the Canadian lay person was concerned, was non-existent. For this newly diagnosed individual with a malfunctioning thyroid gland, it felt like a descent into a medical wasteland where fear, anger and isolation were constant companions. Nevertheless, despite these negative emotions, the frustrating bewilderment, the failure to understand the silence and mystery that seemed to prevail about thyroid disorders, I decided to go public. People needed to know about medical problems that took six years to be diagnosed – about the “all in your head” and “you

From Diana’s Wishes, June 11, 1988 (<https://thyroid.ca/who-we-are/>)

I wish for a World Thyroid Foundation with Chapters in every corner of the globe, where the universal problems of thyroid patients may be addressed.

A MESSAGE FROM THE PRESIDENT THYROID FEDERATION INTERNATIONAL



Dear President, Directors and Volunteers of TFC

On behalf of Thyroid Federation International, we extend our heartiest congratulations to TFC on completing 40 years of volunteer work in Canada. TFC has played a pioneering role in establishing the first Thyroid Patient Organization which was established by its Founder, Diana Hains Meltzer Abramsky. TFC's establishment in Canada inspired other countries to get involved and today around 30 countries (and growing) have a thyroid patient organization and are members of TFI. As a fellow Canadian and as a past President of TFC, I am proud to see the organization thriving and growing over the years.

Forty years is a long time for an organization's existence, and TFC has seen the glorious days (when there was no internet and people met each other in regular meetings), difficult times and changes in the way patients are now receiving education and awareness in this communication age. TFC has gone through all the phases and continues to evolve and remain relevant to the cause. I know numerous people in TFC who have dedicated their time, resources and space to take the organization further. Just to name a few would easily fill a complete page and hence hesitant to omit any. A large number of those great individuals lived long dedicated lives and contributed immensely to the organization. Many of these great volunteers are busy with other initiatives and many are still dedicated with the new volunteers which keep TFC strong and moving ahead.

With your voluntary commitment and dedication you have helped numerous thyroid patients in managing their disease and helping care givers in understanding the thyroid related issues that their loved ones undergo. With your services, the community has gained a lot. I would also like to commend all the Endocrinologists and other healthcare professionals who have dedicated their personal time to the TFC mission. Giving your personal time is one of the greatest gifts a person can give to others.

Wishing a happy 40th Anniversary to the Thyroid Foundation of Canada and all the success for many more years to come. To all the TFC Volunteers, keep up the good work!!

Ashok Bhaseen
President, Thyroid Federation International
A Global Thyroid Patient Organization

Thyroid Federation International celebrates its 25th Anniversary in 2020.

E-mail : tfi@thyroid-fed.org

<https://www.thyroid-fed.org/tfi-wp/>



TFC Past President Ashok Bhaseen receiving an award for service from Mabel Miller



This issue of Thyrobuletin is dedicated to the many volunteers over the past 40 years who gave their time and their hearts to the Thyroid Foundation of Canada.

Some are gone - never forgotten.

We thank you and we celebrate you.

We couldn't have done it with out you!

LOOKING BACK 40 YEARS

TFC ANNIVERSARIES



1990 - 10th Anniversary



1995 - 15th Anniversary and TFI Inaugural Meeting



2000 - 20th Anniversary



2010 - 30th Anniversary



2015 - 35th Anniversary

SOME OF OUR BOARD MEMBERS AND SPECIAL MENTIONS



Rhoda Boyce,
Board Member



Phyllis Mackey
Archivist



Rita Wales
Medical Liaison



Mary Salsbury
Thyrobuletin Com-
mittee



Karl Benne,
Health Canada



Evelyn and Len Freeman
Founding Members



DIANA RECEIVES THE ORDER OF CANADA

(L-R): Bob Gifford, June Rose-Beaty, George Wright, Nathalie Gifford, Diana Abramsky, Mary Salsbury, Laz Bouros, Evelyn Freeman, Karl Benne (Senior Consultant, Health Canada), Phyllis Mackey

TFC PAST PRESIDENTS 1980-2020



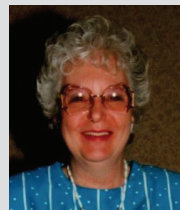
Diana Abramsky
1980-1981



George Wright
1981-1982



J. R. Bestvater
1982-1984



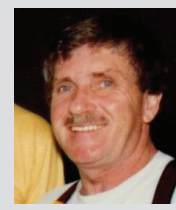
Florence Gore
1984-1987



Joe Boyce
1987-1990



Nathalie Gifford
1990-1993



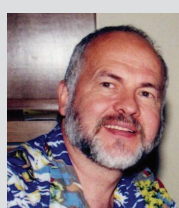
Don McKelvie
1993-1996



Arliss Beardmore
1996-2000



Irene Britton
2000-2004



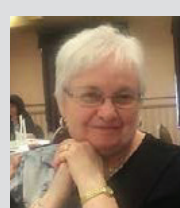
Ed Antosz
2002-2004



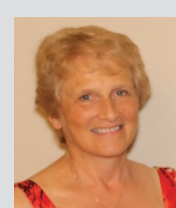
Ted Hawkins
2004-2008



Ashok Bhaseen
2008-2011

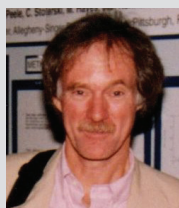


Mabel Miller
2011-2013
2016-2017



Donna Minniely
2014-2016

TFC MEDICAL ADVISORS 1980-2020



Dr. Jack R. Wall



Dr. Robert Volpé



Dr. Gregory Becks



Dr. Jody Ginsberg



Dr. Prakash Chandra



Dr. Deric Morrison

TFC RESEARCH AWARDS PROGRAM



Left: Dr. Marie-France Langlois
Right: Marie-Eve Domingue
University of Sherbrooke QC



Soon-IL Song
Queen's University
Kingston ON



Natalie Kotowycz
Sunnybrook and Women's
College Health Sciences



Maria Diamandis
University of Toronto



Kitchener-Waterloo ON Chapter 1999, (L-R) Sandra Hebert, Derek DeVille, Cassandra Howarth, Joan DeVille.
Still holding Public Education Meetings!



Members of the Ottawa ON Chapter Spring 2003 pictured with their benefactor Debbie Lalonde (seated)



London ON Chapter 2nd Annual Fashion Show April 2002

CHAPTER EVENTS RAISING FUNDS - RAISING AWARENESS



Montreal QC Art Show April 2001
Artists (L-R) Ria Szerszen, Denise Roy, Phyllis Pedicelli, Sharon Goodman (Chapter President), Joyce Pratt & Selma Miller



Toronto ON Chapter Volunteers at the 2004 Women's Health Forum & Expo Booth
(L-R) Beverly Strachan, Marlene Jelski, Lottie Garfield, Ellen Garfield, Laura Mandryk



Seniors Wellness Days Grand Falls-Windsor NL



Margaret Burdsall
President, Kingston ON Chapter



Barb Cobbe, President, London ON Chapter, with husband Chuck



Shirley Penny
Founder, Marystown NL Chapter



Phyllis Payzant
Founder, Halifax NS Chapter



(L-R) Jean Bicheno, Founder Vancouver Chapter, Amelia Hodder, Founder St. John's NL Chapter



Gander NL Chapter Christmas Fair Nov 2002



Hamilton ON Chapter Flower Sale
Nov 2002

Avalon Chapter (St. John's NL) Summer 2003 Display



Andrew Blundon,
Treasurer



(Above:) Kathryn Downton, President,
Grace Bavington, Secretary



Calgary AB Chapter pharmacy display
(L-R) Marlene Depledge, Chapter President,
Irene Peltier, Education



Standing room only - Public Education Meeting - Ottawa Chapter in Hull QC



Pharmacists at Kingston Chapter Monthly Thyroid Education Meetings at Loblaws

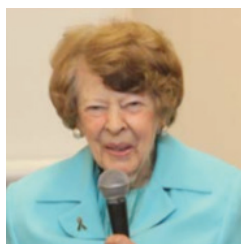
"Friendship" Quilt Raffle
A national fundraiser, quilt made by Mabel Miller and Gander NL Chapter, from material supplied by chapters across Canada, won by Stephanie Diercks, Victoria BC



Kingston ON Chapter Bingo Volunteers, Megan Argue and Dawn Tunncliffe, committed to fund raising



Marjorie Miniely
Founder,
London ON Chapter



Margaret Evans
Founder, Kitchener-Waterloo ON Chapter



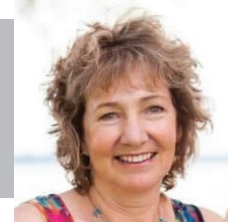
Saint John NB Chapter
Riders for Research 1989



Auction, with Presidents Lois Lawrence, Sudbury and Venette Godbout, Saint John NB Chapter

BEHIND THE SCENES AT TFC

By Katherine Keen



I began working at the Thyroid Foundation of Canada in the spring of 1988 when my daughter was turning 4; I now have a 4-year-old granddaughter! I was studying part-time at Queen's University in Kingston and I was thinking of returning to work so I dropped off my resumé to the HR department. I had worked for a financial institution on Bay Street, Toronto and felt that I would like to work with people, health- or education-related. Not long after, I received a call for an interview and later was offered the job of Office Manager of the Thyroid Foundation of Canada, working 3 days per week. When I told my mother that I was working for the Thyroid Foundation of Canada, she said "Oh, I have that. I just take a little pill every day." I hadn't known that and didn't know anything about thyroid disease.

At that time there were 10 TFC chapters. I was invited to attend a gala in celebration of Diana Abramsky. It was the first time I'd seen Diana. She marched into the room, escorted by a piper in a kilt playing bagpipes. She looked so proud and happy! Soon after, I attended the AGM and was introduced to the Board of Directors which included all the chapter presidents.



Introduction to the Board of Directors, with Sandy Wilson, Office Assistant June 1988

I met so many volunteers over the years who worked for TFC, it would be impossible to mention them all here. The Board of Directors changed every year or so, bringing different personalities, work styles and agendas that I had to adapt to. It could be stressful at times trying to please everyone, but I always felt that I learned something from everyone I worked with.

I got to know Diana well. She called the office regularly and we talked about TFC matters as well as other things - our children, working on our degrees, or my opinion on something she wrote. She often urged me to have my thyroid checked as well as my children's.

I had been feeling very tired and one day when I was visiting my doctor, I suggested that I be tested since it would be ironic if I worked for the Thyroid Foundation of Canada and had an undiagnosed thyroid disorder! A couple of days later, I was called into his office and he told me my thyroid levels were "through the roof". I had a TSH of 38! Diana told me it was the office stress that brought it on.

TFC continued to grow, with more chapters being added, reaching a total of 22 across Canada. Every month my assistant, Deborah Jordan, and I would print out on a noisy, slow, dot matrix printer, 22 sets of various reports, including membership lists with full addresses. It took hours to print the Toronto Chapter's list and we had to stand by because the continuous form paper would often get jammed. We would lay them out in 22 sets on a large board table to be mailed to the chapters.

Membership climbed to over 5,000. Our workdays were increased to 4 days a week. My title was changed to National Office Coordinator. I was directly involved in everything the Board members were doing, as well as routine duties in the office. I attended a number of weekend workshops hosted by Health Canada. We had a Research Fund and gave out annual awards for scholarships and fellowships for thyroid research. The 5-page application form and covering letter had to be printed and mailed to universities across the country. The completed forms and accompanying information were copied and sent to the peer review committee members. By then we had a much better and faster photocopier. TFC's newsletter Thyrobuletin was issued four times per year and mailed to all members.

We moved the office four times; I got used to packing up all the files and supplies! TFC got its own website; Diana came to visit the office and I showed her the website which she was very pleased to see.



Demonstrating TFC's website to Diana

(Continued on page 11)

(Continued from page 8)

Other countries began forming their own thyroid foundations based on TFC and in 1995 Thyroid Federation International was created by Dr. Lawrence Wood from Boston USA, fulfilling one of Diana's list of wishes. I was present for this inaugural meeting in Toronto and later began working part-time for TFI as well as TFC.

We had been receiving an annual operating grant of \$50,000 from Health Canada, but unfortunately, these vital grants came to an end. We applied and received some other grants; however, it became more and more difficult with so many other non-profit groups starting up and all competing for funding. The internet changed everything. People could find out information on their own and didn't need to come to TFC as much. Our membership dropped. Some elaborate events were held to raise funds but they failed and left us in serious debt. Eventually most of the chapters closed, the national office was closed and I was laid off. But thanks to the efforts of a core group, including Ashok Bhaseen and Mabel Miller, TFC was revived and a couple of years later I was brought back on contract, working from home which I am still happy to be doing.

Over the years I have spoken to many thyroid patients with all sorts of problems, some of them in tears as they told me their symptoms and frustrations. While my thyroid symptoms were mainly fatigue, I had other health-related problems, mainly debilitating migraines that started in my twenties. I understand how frustrating it can be to have problems with your health and not finding the answers. My doctors tried various things to help with my migraines, but it was many years before I finally found something that worked for me.

To thyroid patients, I encourage you to not give up; even if you can't find a cure, keep trying, tell your doctor it's still not better; but also look for things that might help alleviate your symptoms.



Katherine and family

THYROBULLETIN EDITORS 1980 - 2020



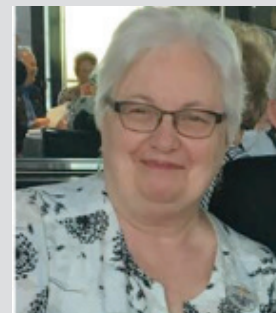
(L-R) Ethan Hollingshead, Bob McTavish, June Rose-Beaty



Ed Antosz



Rick Choma



Mabel Miller

DAGMAR VANBESELAERE



Dagmar VanBeselaere, former Thyroid Foundation of Canada National Board member as well as former Ottawa Chapter president, passes away.

Thyroid Foundation of Canada Board members as well as Ottawa chapter members were saddened to learn that after a brief illness Dagmar passed away on February 3, 2020.

Dagmar had been involved with the Foundation for over 20 years and served in various capacities in both segments of the organization.

Our sympathy to her daughters, Paula and Carla, and their families.



THYROID RESEARCH

As mentioned in our last Thyrobuletin, TFC is looking into entering into a long-term agreement with Canadian Society of Endocrinology and Metabolism (CSEM) to manage our Thyroid research. The TFC research grants will be awarded in the areas of thyroid disease that impact patient care. We are hoping to send the first grant to CSEM by the end of May. The award will be presented to the selected recipient at the next CSEM Professional Conference in October.

The advantages of partnering with CSEM are as follows:

- 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 myself have been invited to be part of the Awards Committee;
- TFC grants will focus on thyroid research that impact patient care;
- The Thyroid research results are vetted by CSEM (research process, etc.) and provide greater legitimacy for the thyroid research;
- By participating in the CSEM Awards Committee, we can gain valuable insight into setting up our own research capability.

In December 2019, we received a Memorandum of Collaboration (MOC) from CSEM. This was forwarded to our Legal Advisors for comment and after several iterations the MOC has been converted to an Agency Agreement. A two-page general Terms of Reference document was prepared by CSEM in February describing the TFC Research Award in general and updated with TFC's suggestions.

Our lawyers are reviewing our Agency Agreement with CSEM. We are hoping to have the Agency Agreement ready for the board's review and approval ASAP.

Laz Bouros
President

Report a side effect of a drug

Have you experienced a side effect with thyroid medications or other health products? Health Canada would like to hear from you. Your report can help make health products safer for all Canadians.

To report a side effect to Health Canada:

REPORT A SIDE EFFECT



https://www.canada.ca/en/health-canada/services/drugs-health-products/mdeffect-canada/adverse-reaction-reporting.html?fbclid=IwAR2edzg6GPchUSDfuEljtyvD7Li_tWBRneJc9Fh3JGT3obxYCmaouAjScc4

THYROID HORMONE REPLACEMENT FOR HYPOTHYROIDISM



Dr. Deric Morrison

(Message received from a member of TFC)

I live in BC, and I was diagnosed with Hashimoto's after the birth of my third child 30 years ago. I was stable for years, but about 20 years ago, when I was about 50, I began to experience symptoms. For about 10 years, my levels went up and down as my doctor adjusted my Synthroid dose according to my symptoms. Finally, I heard about a doctor in Victoria, an endocrinologist specializing in thyroid problems, and my doctor kindly referred me to him. He ordered free T3 & T4, and based on the results, prescribed SR liothyronine in addition to Synthroid. My symptoms improved dramatically. I live in a small, remote coastal town (Powell River), and no one here had heard of prescribing liothyronine in addition to thyroxine for some patients, and there was frank skepticism. However, I've continued to do much better than I was doing before seeing the endocrinologist, though I still have some trouble keeping both levels near target. Also, I find that it can be difficult to get blood work done, as some labs won't do free T3 & T4 and do a TSH instead, even if the requisition is clear.

I know this was controversial some years ago; I don't know if that's still the case. But I wonder if it's a topic you might think worth addressing at some point. I now wonder if my mother, who also was hypothyroid (as are my sister & brother) might not have been like me, needing liothyronine to help keep her free of symptoms. When I look back at how she was, I remember her as being overweight, tired, constipated, irritable, brittle nails, thinning hair, all things that also accompany age, but I do wonder if perhaps she was like me, and how much easier her life might have been if she'd been adequately replaced, assuming she wasn't.

I don't know how many thyroid patients are taking liothyronine. According to the literature I was given, about 20 per cent of us do better with it. I wonder if there are other people who are like I was before I began taking liothyronine, when I was symptomatic and swinging between high and low as my doctor adjusted my Synthroid prescription up and down.

Thank you for any perspective you can offer,
Madeleine F., Powell River BC

(Response from the Medical Advisor)

For a large majority of people with hypothyroidism levothyroxine treatment is effective. Unfortunately, a minority of people with hypothyroidism have persistent symptoms despite what seems to be optimal levothyroxine therapy. It is not yet clear whether combination treatment might help some of these patients. Large high quality randomised controlled trials are needed to address this question. In the meantime for some people with hypothyroidism, after excluding other causes for symptoms, a trial of combination therapy is reasonable with an appropriate dose combination of T4 and T3, and careful monitoring of thyroid function tests and symptoms.

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

*(See our website for more detailed information:
<https://thyroid.ca/resource-material/articles/e-4-p/>)*

Do you have a medical question that might be helpful to other thyroid patients?
Send it to info@thyroid.ca - or Thyroid Foundation of Canada, P.O. Box 298, Bath ON K0H 1G0

THYROID FOUNDATION OF CANADA - CALL FOR NOMINATIONS 2020-2021

The National Board is accepting nominations for positions on the Board for the coming year 2020 -2021.

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 or call 1-800-267-8822. Closing date to be announced.

Mabel Miller,
Nominations 2020 Committee Chair

LA FONDATION CANADIENNE DE LA THYROÏDE - APPEL DE MISES EN CANDIDATURES 2020-2021

Le Conseil national accepte des candidatures pour des postes sur son Conseil d'administration pour l'année 2020 - 2021.

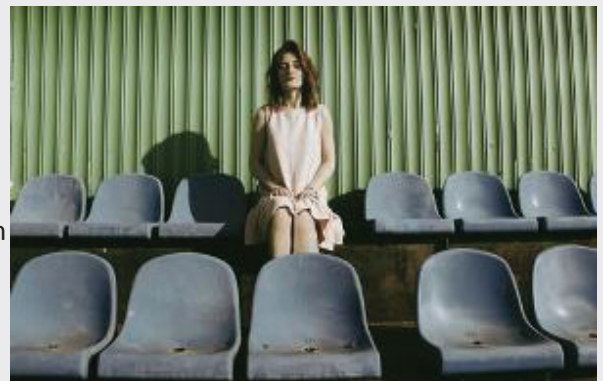
Conformément à l'article n ° 17 (a) - Le Conseil d'administration est composé d'un minimum de sept -- directeurs/trices et jusqu'à un maximum de 15 directeurs/trices élus par les membres en plus du/de la Président(e) sortant (e) si il / elle s'engage à continuer. Si les postes vacants existent au sein du conseil, le Conseil d'administration peut nommer des directeurs/trices jusqu' à un maximum d'un tiers du conseil. Le terme de tout directeur/trice nommé fini à la fin de la prochaine assemblée générale.

Si vous êtes intéressé ou connaissez quelqu'un qui pourrait être intéressé, s'il vous plaît contactez le président du Comité de mise en candidature à nominations@thyroid.ca ou composez le 1-800-267-8822. Date de clôture à venir.

Mabel Miller,
Président du comité des candidatures 2020

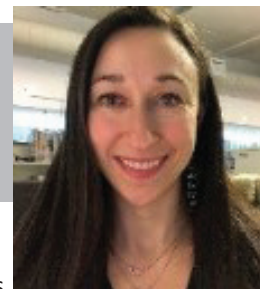
2020 ANNUAL GENERAL MEETING POSTPONED

Sorry, celebrations have been postponed. Yes, this is the year to celebrate the 40th Anniversary of the founding of Thyroid Foundation of Canada and we were hoping to do that at the AGM. Little did we think when we were looking at planning there would be something that would get in the way big time – COVID-19. Stay tuned, more details to follow.



HYPER TO HYPO

By Susey Harmer



I was in my early twenties and in a competitive co-op business program at University of Toronto. It was all very new and overwhelming and I remember feeling consistently stressed with all the reading, studying and job interviews. I had IBS all the time. I was popping antacids regularly just to make it through the day.

I went to my doctor and he did some bloodwork. It turned out my TSH levels were low, meaning I was showing signs of hyperthyroidism. So, my doctor sent me to an endocrinologist in Toronto. I have a very vague memory of what happened next, but I compliantly followed instructions to do what I thought was a test to evaluate my thyroid activity. I was instructed to drink radioactive iodine which was then followed by an X-ray. Instead, as I found out decades later, the purpose of drinking the radioactive iodine was actually to kill the function of my thyroid. In retrospect, I wish I had better understood the procedure and had the time to understand the short and long term repercussions of it. As well, it would have been good to know if there were alternative treatments.

Now, being on the Thyroid Foundation of Canada (TFC) Board of Directors, I have learned a lot from my peers and through reading up on thyroid disorders and treatments on thyroid.ca.

The doctors thought my hyperthyroid condition originated from a virus and based on what I had read more recently, it looked like virally induced thyroid issues can generally resolve on their own without interference. Perhaps it was the only option, but I wish I was armed with more information before undergoing the radiation. That's actually why I wanted to join the TFC, as one of our core missions is to help those with thyroid disorders get the information they need to make informed decisions about their health, and ask the right questions to their doctors and endocrinologists.

Now, I have to take levothyroxine daily for hypothyroidism and still struggle with the associated symptoms. Fortunately, I have a fantastic family doctor who manages my condition by ensuring I have regular blood tests to check TSH levels. I am also extremely fortunate as my doctor is well educated on the fact that TSH levels have a broad range of what is considered 'normal' and what may be a good level for one person may be too high or low for another. It is about how you, personally, feel and then the dosage should be adapted based on your unique needs. For example, we have found the right balance for me has been achieved by taking 0.1 mg five days a week and 0.088 mg twice per week. When I was pregnant with my first child, the attending endocrinologist felt I should increase my dosage and ordered me to have 0.1 mg every day.

The result was that I suddenly started feeling panicked and anxious on a regular basis. In this situation, it was difficult to identify if I was feeling stressed because of daily life or because the dosage was too high. It was a delicate dance finding the right levels. Even now, most of the time, I feel symptoms of both hyper and hypo! The hypo symptoms I regularly struggle with are feeling cold easily, feeling tired and lethargic, and having brittle hair. The hyper symptoms I generally experience are feeling anxious and having a big appetite. So I feel like I'm straddling the two extremes in thyroid disorders: hyper and hypo! I guess I like to be different...

Ultimately, it is about finding a doctor or endocrinologist who can take a personalized approach. It's not just about the numbers, it is how you feel. Keeping regular tabs on your TSH levels is the first step, but the rest is finding the right balance that makes you feel your best. You'd be surprised how many people have thyroid disorders. Talking to others and hearing their personal journeys is comforting and can make you realize that you shouldn't settle for feeling mediocre... you need to fight to live your best life.

Encourage everyone you know to visit thyroid.ca. There is lots of great information, and by supporting the foundation, the TFC can continue to support patients, like us, across Canada.

Susey Harmer
TFC Director of Fundraising



Susey and Family

A GRAVES' DISEASE/MENTAL HEALTH TRAGEDY

By Dr. Jack R Wall



Depression and psychosis are uncommon but well-known features of Graves' disease and suicide is twice as common in Graves' patients than in age and sex matched control subjects without Graves' disease. This is highlighted by a recent and very sad (Australian) case with a tragic end that resulted from the concurrence and merging of medical and environmental factors, which reminds us all to be vigilant for the development of mental health changes in patients with Graves' hyperthyroidism.

This report concerns a young female patient (J-) with Graves' hyperthyroidism who had been treated with an anti-thyroid medication for more than 3 years, who became increasingly confused, anxious, depressed and fearful over a two weeks period leading to her suicide. She also had a liver disorder that was probably due to the Graves' disease itself or an allergy to the anti-thyroid drug. There was a background of workplace pressure of uncertain nature and fear of the radioiodine (RAI) treatment that had been planned. All her health carers did their best under challenging and stressful circumstances and no major errors appear to have been made.

J- was treated with courses of Neomercazole (NZ) over a 3½ year period. Some endocrinologists start with small doses of the drug, increasing as necessary to slowly bring the thyroid hormone levels down to normal, whilst others like to get control of the hyperthyroidism quickly by starting with a larger dose of the drug and reducing slowly to maintain euthyroidism. In both cases treatment is usually for 12 – 18 months. Without knowing the results of all of the thyroid tests carried out during the 3½ year period, or the NZ doses prescribed, it is likely that her endocrinologist would have treated her for a year then, following relapse, offered her definitive therapy with RAI. The decision to finally go ahead with RAI treatment was correct. The various investigations carried out during the last two weeks of J-'s life, and the management of her evolving health issues at that time, appear to have been appropriate.

In Canada (and even more so in Australia), many Graves' patients are afraid of RAI, even though the long-term success rate of anti-thyroid medication is only 50% (in other words half of them relapse within a few weeks of stopping the drug) and despite the fact that RAI is the initial, and thus only, treatment in 75% of Graves' patients in the US, as described in the American Thyroid Association (ATA) guidelines that most endocrinologists like to follow. RAI is safe, specific - the classical "magic bullet" - and efficacious, but most patients eventually require thyroxin replacement in the long term as the treatment dose of RAI is a deliberate attempt to eliminate the thyroid gland and render the patient hypothyroid.

However, this should not be a deterrent since about 10% of all women will eventually be treated with thyroxin for one reason or other. While recent studies suggest a small positive association between greater organ-absorbed doses of radioactive iodine and risk of solid cancer, the ATA states that "there has been no clear increase in thyroid or other common cancers with regard to exposure to RAI". RAI has been used to treat Graves' disease for more than 80 years and it seems unlikely that the possible remote development of some cancers should be considered a complication of this well tested therapy. However, these recent findings are of concern for both patients and endocrinologists and more long-term prospective studies are needed.

A third option is surgery to remove the thyroid gland, so-called subtotal thyroidectomy. While this provides an immediate cure of the Graves' hyperthyroidism – a "quick fix" - the patient, who is now hypothyroid, must be treated with thyroxin replacement following surgery. In addition, there are some important complications of the surgery, namely, damage to the nearby parathyroid glands (and the development of hypoparathyroidism) and the recurrent laryngeal nerves which control vocal cord function. However, in the hands of an experienced endocrine surgeon, these complications are uncommon. Neck swelling and some hoarseness can be expected for a few days following thyroid surgery.

In the case of J-, it seems that the endocrinologist did his best to manage the increasingly difficult circumstances that characterized J-'s final two weeks. Her thyroid hormone levels were quite high initially and I expect that she would have been given a large dose of NZ at that time, which was then reduced down to interval between the first relapse of her hyperthyroidism and her agreeing to have RAI treatment.

The main lesson to be drawn from this tragic case is that we must look carefully for the development of depression, anxiety and paranoia in young female patients with Graves' hyperthyroidism who may be most at risk. We understand that accepting RAI treatment is a difficult decision for many patients to make. There is always anecdotal advice available (to the patient) about the presumed "dangers" of RAI, whereas we know that in truth this is a very good treatment that has been described by some as the best treatment for any disease, the classical magic bullet that targets only the thyroid follicular cells.

(Continued on page 17)

(Continued from page 11)

Endocrinologists should make a greater effort to convince patients about the merits of RAI treatment as initial treatment of their hyperthyroidism. Once patients have agreed to go ahead with RAI treatment, either after a relapse following 12 – 18 months of antithyroid drug medication, or as the initial treatment, the managing endocrinologist must warn their patient that any ophthalmopathy (eye signs) can temporarily worsen following RAI treatment but, in the longer term, will improve as the thyroid proteins that drive the autoimmune reactions in the orbit are destroyed. Female patients who have not reached menopause must agree to avoid pregnancy for at least 6 months following RAI.

What can we do in the future to educate patients with Graves' disease, their partners and where appropriate, other family members and close friends about the need to look carefully for signs of depression and psychosis, in particular paranoia, and when should urgent psychiatric help be sought? We must take the time to discuss the patient's illness with close family members who are in the best position to observe and react upon warning signs of mental health disease. Moreover, we know that patients often report that their close family members do not understand how hyperthyroidism affects the brain. Unfortunately, the patients may not realise that these

brain. Unfortunately, the patients may not realise that these changes are manageable with correct treatment, so they are unable to educate their support team appropriately. A less than full understanding of the relationship between mental health disease, especially any feature of a psychosis such as paranoia, and Graves' hyperthyroidism, by patients and their family carers alike, can lead to tragic consequences such as related here.

Finally, in an ideal world, the development of severe depression (e.g. where suicidal thoughts have been experienced and reported), or psychotic symptoms such as paranoia in a patient with Graves' disease, would be recognized as red flags for urgent psychiatric review and management. At the least, this case should remind us to be more vigilant for a rare but potentially tragic association.

Jack R Wall MD, PhD, FRACP, FRCPC
Honorary Professor of Medicine, Macquarie University, Sydney
Consultant Endocrinologist, The Bays Hospital, Morningside Vic
Australia

First Medical Advisor to the Thyroid Foundation of Canada

Hyperthyroid Medication Discontinued

The Thyroid Foundation of Canada has recently learned an important medication for hyperthyroidism, Propylthiouracil (PTU) has been discontinued by Paladin Labs, the only Canadian manufacturer of PTU. The Canadian Society of Endocrinology and Metabolism (CSEM) has written a letter of concern to Health Canada ([link to CSEM letter on our website](#)). In 2018, there were about 36,000 prescriptions for PTU.

Patients who are concerned about this should consult with their doctor re other possible treatment options as well inform their MP regarding the discontinuance. There is an alternative drug, Methimazole (Tapazole), however some patients may be allergic to it and it is not recommended for pregnant women.





HYPOTHYROIDISM

Facts to know about

The Thyroid Foundation of Canada and BGP Pharma ULC (doing business as Mylan), have co-sponsored videos on hypothyroidism to promote public awareness.

Now available on our website: <https://thyroid.ca/new-videos-on-hypothyroidism/>
Great information to pass along to family members since thyroid disease can be family related.

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: <https://thyroid.ca/bequest/>

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

THYROID DISEASE AND CORONAVIRUS (COVID-19)

Are Individuals With Autoimmune Thyroid Disease At Increased Risk Of COVID-19 Infection?

Excerpt from an article published by the British Thyroid Foundation.

COVID-19 is a new virus, so we have no information on how it affects individuals with thyroid disease. However, thyroid disease is not known to be associated with increased risk of viral infections in general, nor is there an association between thyroid disease and severity of the viral infection.

Many people are asking whether having an autoimmune thyroid disease means you are immunocompromised. We can confirm it does not. The part of the immune system that's responsible for autoimmune thyroid conditions is separate to the immune system that's responsible for fighting off viral infections, such as COVID-19.



Patients who are classified as having a weakened immune system (immunocompromised) are typically those with conditions such as leukaemias, HIV and AIDS, or who are on medicines such as high-dose steroids, immunomodulatory drugs for rheumatoid arthritis or multiple sclerosis, cancer chemotherapy or following organ transplantation.

Read the full article:

<https://www.btf-thyroid.org/news/thyroid-disease-and-coronavirus-covid-19>

QUILT FUNDRAISER, GANDER, NL



Thyroid Foundation of Canada Ticket Lottery

Handmade Quilt – 100% cotton, double bed size
Made by a Group of Thyroid patients in Gander, NL

To be drawn September 25, 2020

For more information, please contact us:
800-267-8822 info@thyroid.ca

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.

May	Thyroid Disease, Pregnancy & Fertility
June	Thyroid Disease... Overview of thyroid function
July	Surgical Treatment of Thyroid Disease
August	Thyroid Disease and Seniors
September	Thyroid Nodules

Visit ***thyroid.ca*** each month to read our Thyroid Topics

MEMBERSHIP AND DONATION FORM

Name:

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MEMBERSHIP LEVEL

ONE YEAR:

TWO YEAR:

☐ Regular \$35 ☐ Senior \$30 ☐ Family \$45

☐ Regular \$60 ☐ Senior \$50 ☐ Family \$65

TOTAL AMOUNT

\$ **Membership** *(All members receive Thyrobuletin)*

\$ **Donation** *(All donations support the work of the Thyroid Foundation of Canada)*

\$ **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 K0H 1G0 - or pay online at ***thyroid.ca/donate***

Thank you for your support!