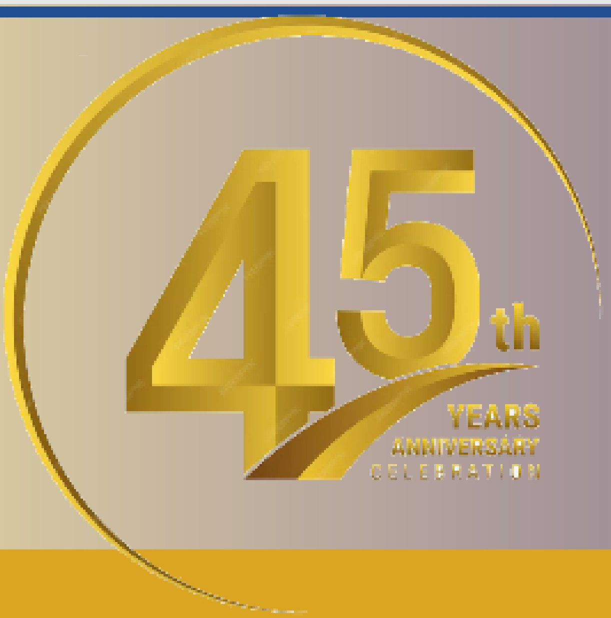
Thyrobulletin

Spring 2025



1980 - 2025

Webinar: Thyroid Eye Disease Patient Panel

Read Sylwia's Story

Thyroid Foundation of Canada
La Fondation canadienne de la Thyroïde

Founder
Diana Meltzer Abramsky, C.M., B.A.
1915 - 2000

Providing education, patient support and thyroid research since 1980

Thyroid Foundation of Canada

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Thyrobulletin is the official newsletter of the Thyroid Foundation of Canada.

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MESSAGE FROM THE PRESIDENT

Dear members,

This June we are celebrating our 45th anniversary! It's amazing how much everything has changed since the old days. In 1988-90, when I was volunteering with the Ottawa Chapter, everyone met in person and our public education events were held in the Blue Room at the Ottawa Civic Hospital. We had a great turnout at these educational events with coffee, tea and cookies provided for attendees. In those days, TFC had 24 chapters across Canada and a brick and mortar office in Kingston! These days we operate virtually, have no chapters and no physical office. Somehow, we managed to survive all the ups and downs, recessions, and COVID and here we are 45 years later. This June, we're going back to having an in-person AGM in Toronto!

This year, to celebrate our anniversary, we have our very own song about thyroid disease on YouTube to help promote thyroid awareness, see Working on the Thyroid Line and we are starting a new section in our website called "TFC Pioneers!" This section will serve to showcase all those volunteers whose contributions helped to make TFC a success! If you know of key players such as National Presidents, Chapter Presidents and others, please forward your 200-300 word write-up to us at info@thyroid.ca and we will add it to this section. Photos are a good idea too!

Awareness/Education
Last November, we partnered with Celiac Canada to present an educational webinar on Autoimmune Thyroid Disease and Celiac Disease. On April 25th, Donna Miniely gave an excellent thyroid overview presentation to the community senior social group at Queen Square Family Health Team in Brampton, Ontario. We also held a very successful Thyroid Eye Disease Patient Panel webinar with Dr. Kelsey Roelofs on April 27th. Unfortunately, the Research Award Results presentation in May with Dr. Sana Ghaznavi will be rescheduled. We created a new Hypoparathyroidism Health Guide with a grant from Pendopharm to support a small group of thyroidectomy patients.

Recently, we established an education partnership with the Canadian Society of Endocrinology and Metabolism (CSEM) to co-sponsor educational webinars so that both CSEM and TFC members and the general public could attend these educational events.

Advocacy
This past year, our advocacy efforts have really taken off. Last fall we completed our first Health Technology Assessment with support from a health consulting organization.

Recently we were approached by the Canadian Cancer Society (CCS) and we agreed to support their HTA submissions relating to thyroid cancer. We became a member of CanCertainty to improve the affordability and accessibility of cancer treatment, the Canadian Organization of Rare Disorders (CORD) to help support thyroid eye disease and hypoparathyroid patients and the CATALIS group in Quebec to support clinical trials of thyroid related drugs in Quebec. We were contacted by Canada's Drug Agency (CDA) for one of their non-sponsored reviews to find a thyroid cancer clinician with experience with Dabrafenib-trametinib for BRAF V600E mutant anaplastic thyroid cancer as well as a patient with lived experience.

Support
We continue to provide patient support through our toll-free Help Line and email. We started referring thyroid cancer patients from our Help Line who require additional personal support to the Canadian Cancer Society's CancerConnection. This is a safe space where you can connect, learn and share your stories with people with similar experiences with cancer.

Research
On November 2024, TFC's $50,000 award for thyroid research was presented to Dr. Anna Sawka at the CSEM AGM in Halifax. Last March, TFC provided a letter of support for Dr. Sana Ghaznavi and Dr. Caitlin Yeo who have applied for a research grant through the University of Calgary Department of Surgery's "Pathway to Success (PTS) fund". The deadline for submissions for next year's research award deadline has been moved to April 30th, 2025, at CSEM to allow more time for research submissions. See Thyroid Foundation - CSEM The Canadian Society of Endocrinology and Metabolism for details.

To volunteer, donate 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 happy and safe summer!

Laz Bouros,
President

LAURI MARTIN LEAVES TFC

We deeply regret that Lauri Martin, one of our long-time board members, has resigned from the board and all her TFC activities. Lauri has experienced a lot of change in her home life over the past year and has recently moved to southern Alberta. She is now providing more care and support to her family and finds herself with little time left for TFC.

Lauri started volunteering for TFC back in January 2018. She has been Director, Volunteer Recruitment and Development for many years and has been an active member of the Help Line Team, Nominating Committee, Webinar Support Team and Social Media Team. She managed our volunteer recruitment in an exemplary fashion, provided advice to improve our services, was quick to respond to emails and the first to pickup calls from the Help Line.

She will be greatly missed by all. We thanked her for her years of support and invited her to attend our AGM this June so we can show our appreciation for her.

45th ANNUAL GENERAL MEETING

SATURDAY, JUNE 21, 2025
09:00 - 11:00 AM ET

FOUR POINTS BY SHERATON TORONTO AIRPORT

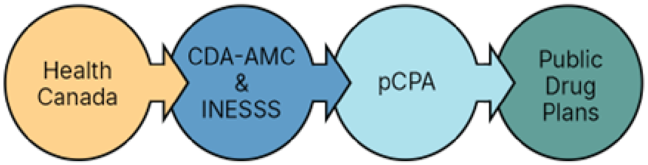
Everyone is welcome
TFC Members are eligible to vote

Please register: info@thyroid.ca

CDA NON-SPONSORED REVIEW PROCESS

Canada's Drug Agency is a not-for-profit organization responsible for providing health care decision-makers with objective evidence to help make informed decisions about the optimal use of health technologies, including drugs, diagnostic tests, medical, dental, and surgical devices, and procedures. In addition to evidence, they also provide advice, recommendations, and tools. They do not make decisions about funding, nor do they conduct clinical trials. They gather, review, appraise, and summarize the available evidence for decision-makers. Projects come to them from provincial, territorial or federal jurisdictions, health authorities, hospitals, or pharmaceutical companies, or they initiate them.

Recently, TFC was asked by the Canadian Drug Agency (CDA) to participate in their non-sponsored review process for Dabrafenib-trametinib for BRAF V600E mutant anaplastic thyroid cancer. Unlike sponsored reimbursement reviews where drugs must have Health Canada approved indications, a non-sponsored review may consider off-label indications if identified by clinicians and drug programs to address any unmet need.
CDA will prioritize non-sponsored reimbursement reviews based on advisory committee priority, availability of evidence, and capacity.



Canadian Drug Reimbursement Process Overview
1. Health Canada reviews drugs for safety, efficacy and quality before authorizing them for sale in Canada. This authorization results in a Notice of Compliance (NOC).

2. CDA and INESSS provide a recommendation to public drug plans on whether or not a drug should be reimbursed for public funding.

3. pCPA uses the recommendations from the CDA and INESSS and other factors to determine whether or not it will enter into a negotiation for a drug. Following a successful negotiation, pCPA will issue a letter of intent which sets the terms of the agreement between the pCPA and the drug manufacturer.

4. Public drug plans make a final decision to fund a drug once a negotiation has been successfully completed and enter into a product listing agreement with the drug manufacturer.

When sponsors of the branded drug have declined to file an application with the CDA, CDA will consider reviewing a drug through the non-sponsored reimbursement review process for clinical indications for which a pharmaceutical manufacturer has not applied for a Health Canada Notice of Compliance (i.e., off-label use) when there is evidence of use of the drug for the condition of interest in Canadian clinical practice (e.g., integration of the drug into clinical practice guidelines, consultations with clinical specialists). If requested from public drug programs, drugs will be eligible when at least 1 of the following circumstances apply:

- clinical data are available for the indication of interest, to permit the CDA and the expert committees to evaluate the effectiveness of the drug;
- approval for use of the drug for the indication of interest has been issued by other regulatory authorities (e.g., US FDA or the European Medicines Agency); or
- there are existing international health technology assessment recommendations in favour of reimbursement.

CDA will prioritize non-sponsored reimbursement reviews based on advisory committee priority, availability of evidence, and capacity.

The pilot Formulary Management Expert Committee (FMEC) provides recommendations to CDA's non-sponsored single drug reviews, streamlined drug class reviews, and therapeutic reviews. The expert committee includes a patient expert member who has equal voting rights to other expert members. A person with experience (patient, family, caregiver) of the condition and medication(s) under review is invited to present directly to the expert committee, and to answer questions from the committee members. Their insights and perspectives help us understand the disease area, and the Canadian healthcare landscape more comprehensively for those living with the condition.

A summary of the patient contributor's presentation is included in the final recommendation as well as they are thanked by name for their contribution. An optional debrief meeting is available after the engagement session to offer support and discuss the engagement. This is completely up to the patient and not a requirement.

AN AMAZING THYROID CANCER STORY!

Last fall we were approached by the Canadian Drug Agency (CDA) to help them with a “non-sponsored review” for the treatment for a rare mutant anaplastic thyroid cancer. I reached out to the thyroid cancer doctors I knew to find clinicians with this type of expertise to assist with this review. We received a lot of collaboration for this request and wound up contacting a total of 12 clinicians in the thyroid cancer area. We found three who offered to volunteer with this review! In December, CDA asked as for a patient with lived-in experience. I went through the same contacts in January and we were able to find a patient with this rare type of condition. It was just an amazing physician/TFC/CDA collaboration!

In March, CDA invited me to participate in their Formulary Management Expert Committee (FMEC) virtual review. This included listening to the audio interview of the patient and the clinical presentation and review of the treatment. (I was not allowed to be present for the subsequent committee discussions).

To give you an idea of what this disease involves, I’ve included the following summary taken from the CDA draft recommendation.

“A Person with Lived Experience in Ontario and his wife shared their journey with anaplastic thyroid cancer after a diagnosis in 2022. After experiencing neck discomfort and swelling, his condition deteriorated rapidly leading to hospitalization for over a year. He underwent emergency surgery and received radiation therapy with little success. As his symptoms worsened, he required a tracheostomy and a G-tube for nutrition. Doctors initially gave him three months to live, but genetic testing revealed he had the BRAF V600E mutation, leading to initiating treatment with dabrafenib and trametinib. Within weeks, his swelling reduced, his mobility increased, and they noted a significant improvement in their quality of life compared to chemotherapy. He remains on the treatment without the need for a G tube, and other than fatigue and slight pain, he has minimal side effects compared to radiation, which he described as an acceptable trade-off for him to be present for his family.”

CDA informed us Friday that their draft recommendation has been posted on their website.

“The Formulary Management Expert Committee (FMEC) recommends that dabrafenib-trametinib, be reimbursed in adults for the treatment of unresectable or metastatic BRAF V600 mutant anaplastic thyroid cancer, provided certain conditions are met.”

I thanked all the physicians for collaborating to help us make this CDA Non-Sponsored Review possible and for finding a patient who has recently lived with this condition! I’m very happy that TFC not only helped to make this thyroid cancer treatment available but to also establish a good working relationship with CDA!

Laz Bouros

HEALTH CANADA APPROVES TEPEZZA

Health Canada approved the teprotumumab (Tepezza) drug for thyroid eye disease on April 17, 2025.
See **Product information**.

TEPEZZA from Amgen Canada “reduces eye bulging and double vision. It also improves the signs and symptoms of Thyroid Eye Disease (TED), including eye pain, redness, and swelling.” Approval by Health Canada is the first step in the four-step process. The next step is the recommendation for reimbursement by CDA and INESSS in Quebec expected in May 2025. Steps 3 and 4 will take 12 or more months to complete. TFC will provide updates for TED patients as additional steps are completed.

RADIOFREQUENCY ABLATION FOR THYROID NODULES: A NEW APPROACH TO TREATMENT

Research Project Lay Summary
Sana Ghaznavi, MD, FRCPC

The Problem We're Addressing
Many Canadians develop thyroid nodules during their lifetime. Currently, there are limited treatment options available:

- **Surgery** to remove part or all of the thyroid gland, which carries risks of vocal cord nerve injury and almost always results in the need for lifelong thyroid hormone medication
- **Radioactive iodine** treatment, which exposes patients to radiation and often leads to the need for lifelong thyroid hormone medication
- **Active surveillance** (watching and waiting), which requires indefinite follow-up appointments and can cause significant anxiety about living with an untreated condition

All of these options have significant drawbacks, particularly the fact that surgery and radioactive iodine typically result in hypothyroidism—a condition where patients must take thyroid replacement hormone for the rest of their lives. Many patients experience persistent symptoms and reduced quality of life despite medication.

Our Proposed Solution: Radiofrequency Ablation (RFA)
Radiofrequency ablation is a minimally invasive procedure that has emerged as a promising alternative treatment for thyroid nodules. During RFA:

- A thin needle is inserted into the thyroid nodule under ultrasound guidance
- The needle delivers heat energy that destroys the nodule tissue
- The procedure can be performed as an outpatient visit without general anesthesia
- RFA preserves normal thyroid function, avoiding the need for lifelong medication

While RFA is increasingly used internationally, it remains largely unavailable in Canada. Some of the centres that are offering it are only doing so as an out-of-pocket expense such that it remains inaccessible for most patients.

Our Research Study
We propose to establish Alberta's first program for radiofrequency ablation for thyroid nodule treatment. Our study will include 40 patients with three different types of thyroid nodules:

1. Hormone-producing nodules that cause hyperthyroidism
2. Large benign nodules that cause symptoms like difficulty swallowing
3. Small, low-risk thyroid cancers that would otherwise require surgery or lifelong monitoring

We will evaluate how well RFA works for each group, track any complications, and measure changes in quality of life. Patients will be followed for up to one year (longer for those with thyroid cancer).

Expected Benefits
If successful, this research could:

- Establish the first thyroid RFA program in Alberta
- Provide patients with a treatment option that preserves thyroid function
- Eliminate the need for lifelong thyroid hormone medication for many patients
- Reduce healthcare system costs by decreasing dependence on operating rooms and eliminating long-term follow-up needs
- Form the foundation for a larger Canada-wide study that could make this technology more broadly available through our public healthcare system

Why This Matters to Patients
For patients with thyroid nodules, RFA offers the potential for effective treatment without the significant quality of life impact that comes with current approaches. By preserving normal thyroid function and avoiding the challenges of managing thyroid hormone replacement, RFA could significantly improve patient well-being while providing definitive treatment.

This study represents an important first step toward making this innovative approach publicly available to all Canadians.

ASK THE DOCTOR: FROM OUR WEBINAR ON THYROID EYE DISEASE PATIENT PANEL WITH DR. KELSEY ROELOFS

Q1. I've had Graves' eye disease for 40 years. My condition was stable until four years ago, then one eye started protruding more and my vision worsened; the pressure also increased. It's stable now, but I'm wondering if this is common and what could cause it?

A1. It is not common, it's pretty rare to have, I'm making an assumption here that there was truly a reactivation of your thyroid eye disease with worsening of proptosis, but reactivation of thyroid eye disease is pretty rare. I tell my patients the chance of that happening once they've hit the inactive phase, and we've finished all of the rehabilitation work that we're doing is about 3%. It's slightly more common in smokers, so nobody with thyroid eye disease should smoke, that's the most impactful modifiable risk factor, and then I think the potentially worrisome thing that you mentioned is about the vision change. That really needs to be looked at by someone who is an ophthalmologist or an oculoplastic surgeon. We have a hierarchy of things that we prioritize in all of our personal lives and in all of these different medical conditions that we as doctors manage, they are all important but vision is super important and sometimes there is a limited time window where we can address problems that are causing issues with the vision, and so I would say from that whole story it's uncommon but if you have thyroid eye disease and you're noticing vision changes that is an urgent visit to your eye specialist because they need to check and see exactly what's going on and, if something urgently needs to be done, to manage it.

Q2. My Graves' eye disease is currently stable, but they are always tired, sore and extremely sensitive to light. My eyes often do not work together, and I lose the ability to focus, I often find it hard to focus on faces particularly if the person is taller than me. Will it always be this way or is there anything that I can do to help these symptoms?

A2. The message I want to leave you all with is that I don't believe anything will always be this way, I think there's always small things that we can do to make things better, even if we can't totally get rid of things. Your symptoms are pretty common for someone who has what we call inactive or stable thyroid eye disease, the irritation and the fatigue and some of the light sensitivity. It all depends on the individual situation, and what the best treatment option is for that. I think there are a lot of differences in approach to thyroid eye disease amongst physicians and surgeons and it all depends on how impactful your symptoms are, whether it's worth going through something for a small change, but I've done many decompressions for people with 1 or 2 mm of proptosis that are totally life-changing because it probably gives them an improvement in some of the congestion in the orbit, an improvement in the exposure of the ocular surface which improves some of the light sensitivity and the dryness and the grittiness. So I think the key is being assessed by someone who knows the armamentarium of things that you might be a candidate for and then trying to personalize or customize the approach, not looking so much at the numbers or always the objective appearance but looking more at the change from baseline. I always get my patients to bring in old photographs of themselves before they had thyroid eye disease because I'm sure any of you who have thyroid eye disease, you've had a Hertel measurement, normal for a Caucasian person is less than 21 but I have patients who range from 15 to 24 and they're all normal and that's huge. So trying to get you back to who you are, not get you back to the normal range, I think is the important thing to appreciate and so, yes it's not always going to be that way, I'm sure there are things that can be done, whether it's eye socket surgery, eye muscle surgery, eyelid surgery, medical management, it totally depends on the individual situation, but it's important to consult with somebody who knows the whole spectrum that's available.

Q3. If Tepezza is approved in Canada, would it be very expensive. I've heard as much as $100,000? Also what are the side effects?

A3. I have some exciting news that actually I heard from Amgen, the company that markets and sells Tepezza, that Health Canada did approve it last week, so it is coming to Canada. There are a lot of steps ahead and I won't pretend to be an expert on the whole drug approval process, but it will be available. I will say, this is my personal opinion, is that it's not an appropriate medication for everybody and I think or at least I'm hopeful that the implementation in Canada will be a little bit more, maybe regulated is the wrong word, but I was practicing in the US from 2020 to 2024 and I definitely saw a dramatic shift throughout that 4-year period of how it was being prescribed and what it was being used for and so I think the benefit of it coming to Canada now after we do have more real world experience, is that we have a better sense of who it's best for. There are people who it's absolutely critical for, and as a surgeon I'm super excited to be able to have it back in my armamentarium to offer people. But it's definitely not for everybody and so again it comes down to the personalization. You asked a great question about pricing; again not an expert, the price will definitely be different than in the United States, how it's going to be administered will be different than in the United States, the US is a for-profit system and so I'm not sure exactly what the prescribing patterns are now but initially it was like everybody was prescribing Tepezza whether or not they were adequately monitoring the eye condition itself. I hope there will be more responsible prescribing of it and regulation and that it will be used for a tighter, narrower group of people who it's really beneficial for. I also think the drug company, I've had some great experience with them and I'm optimistic that for certain people who need the drug urgently, for example someone who has vision loss from thyroid eye disease, that the company may be able to fund some of those cases directly so that there's not a delay in waiting for government processing. So I think a lot of the specifics need to be worked out but I'm super excited that it is going to be available, we just need to think about how to best responsibly use the medication and customization of thyroid eye disease, that's the future of medicine, it is a personalization of everything and helps us do a better job at customizing treatments and outcomes for patients.

Q4. I had a hemi-thyroidectomy two years ago for papillary cancer. Since then, my eyelids have swollen and are fluid filed. I have seen a plastic surgeon, but he felt that surgery would not help and that this is an underlying issue. My endocrinologist has no idea what it could be. What would be my next steps, as this has really changed the way that I look?

A4. I don't want to get into asking you medical questions on a webinar but there are lots of reasons to have puffiness or swelling in your eyelids it'd be atypical if you had papillary thyroid cancer for that to be fully explained by thyroid eye disease by the pathophysiology and the mechanisms and the antibody interaction that we understand the disease currently, so I think honestly following up even with someone like your family doctor, having them make sure your heart and your kidneys are processing fluid properly sometimes when you have generalized body retention I have certainly seen it present many times where the eyelids are the first or even the only sign of it because the eyelid skin is super thin it's like a millimeter thin it's the thinnest in the body and so when you have a net surplus of free water in your body it might be the only place that's puffy, especially if it's worse in the morning when you first wake up because overnight you've been laying down and gravity's been kind of helping it migrate into those really thin tissues so it may not be thyroid eye disease related. I would definitely have a full checkup with your doctor to see what else could be going on.

Q5. I have been managing Graves' for three years on tapazole and am now having many of the symptoms of TED, such as socket pain, double vision, as well as central vision in only one eye due to an unrelated issue. The diplopia has seriously impaired vision such that computer-based work is quite difficult. I have been unable to identify a specialist with expertise in TED in my province and my first question is if anyone in Canada is addressing this disease from the autoimmune perspective?

A5. You're not alone in feeling like the double vision is really debilitating. Of all the different types of patients that I see those with double vision feel like most impaired from performing their activities of daily living including going to work especially if they work on a screen. I think Laz had mentioned maybe the Canadian Society of Oculoplastic Surgeons has a website and we have directory which shows a list of oculoplastic surgeons in every province. Not all oculoplastic surgeons have an interest in TED but all at least have a functional capacity to manage and direct your TED related concerns or at least assess them. So I would start by having your family doctor refer you to an oculoplastic surgeon and then whether anyone is doing research on the antibody relationship. There's tons of research going on in TED, obviously the Canadian community is much smaller than the American community which includes many Canadians who participate actively in that society, there is a whole session of our annual meeting that's dedicated to TED and so we look at a lot of studies that are clinical but also some basic science type studies where we're looking at antibodies and pathways within the tissue that are leading to some of these debilitating concerns like diplopia. So it's definitely an active area of research, I know thyroid eye disease is relatively rare but for oculoplastic surgeons it's not and so within our community it's an ongoing area of research.

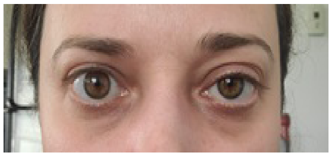
This webinar can be viewed at: https://thyroid.ca/thyroid-disease-2/thyroid-webinars/

MY JOURNEY WITH GRAVES' AND THYROID EYE DISEASE

By Sylwia Sajdyk

My mother was the first to notice something was wrong with my appearance back in February 2020. Knowing my face well, she sounded the alarm and thankfully, I acted quickly. I went to my family doctor and was diagnosed with Graves' disease shortly after.

Even though I was diagnosed quickly and started on methimazole right away, I found the medical system incredibly hard to navigate from the beginning. It took months to get an appointment with an endocrinologist. In the meantime, no one was monitoring my thyroid levels. My family doctor gave me a dosage but no instructions on follow-up testing, and as a result, I became severely hypothyroid and gained 20 pounds in a short span of time.


Before drug trial

The lack of guidance about treatments, timelines, and expectations persisted for quite some time. My endocrinologist, though clearly stretched thin, was often available for only a few minutes over the phone, and early on I struggled to understand what to expect. Each appointment or test felt like its own puzzle. I cycled through confusion, frustration, and moments of despair. Would I ever get through this? Would I ever recognize my eyes again?

I was referred to two different oculoplastic surgeons. Both gave me the same difficult news: I'd have to wait until my TED became inactive before I could consider surgery and even then, outcomes could vary. Some patients, they warned, may not see the improvement they hope for. It was a sobering reality.

For a while, I felt lost, unsure how to move forward. But I gradually started finding clarity through a mix of trusted medical care and my own initiative. Online support groups became a helpful supplement, connecting me with others in the same situation and offering insights into patient experiences. Through them, I learned about treatments like monoclonal antibodies, specifically teprotumumab (brand name Tepezza), which, sadly, remains out of reach for patients in Canada.

That discovery sparked a new wave of advocacy in me. I began searching for drug trials. After a year, I found one through Viridian Therapeutics in Detroit. Starting in October 2024, I made long drives across the border to receive infusions of VRDN-001. My TED improved modestly, just under 1mm with the drug and some reduction had already occurred naturally as I moved closer to remission. My right eye remains affected by upper eyelid retraction, which I plan to address surgically.

But I'm in a very different place now. TED no longer dominates my life. I've returned to many of my old routines, and Graves' disease is now in full remission, with undetectable TRAb levels. For that, I am grateful.

While the journey was not without complications, I want to acknowledge that my endocrinologist ultimately played a crucial role in helping me reach this point. Managing Graves' disease is complex, and I know how demanding the field is. Your guidance, even when time was limited, helped bring stability back to my health.

Looking to the future, I hope endocrinologists will become the first line of defense against TED, recognizing early signs and, when treatments like monoclonal antibodies become available in Canada, initiating care immediately rather than waiting months for referrals. The current system feels fractured, with patients often left to coordinate between multiple specialists. It would be ideal if endocrinologists could take a more comprehensive and integrated approach, managing both Graves' and TED proactively, ensuring no time is lost and no patient feels left behind.

To the endocrinologists reading this: thank you. I hope my story reminds you how impactful your care is, especially when dealing with a condition as multifaceted and emotionally taxing as TED. Patients like me benefit most when medical expertise and patient-led advocacy work hand in hand. Together, we can change the experience for future patients for the better.

Sylwia is a Project Manager at an Architecture firm and specializes in Residential Design.

Pictured left, Sylwia in her art class.

What's your story?

Do you have a thyroid story you could share with us? Our readers find the experiences of others to be very helpful in their own struggle with thyroid disease. Please send your 500-1,000 word story and a couple of photos to: info@thyroid.ca

THYROID ARTERY EMBOLIZATION (TAE)

As a result of request from a Help Line caller, we discovered a new type of treatment for patients with thyroid goiters with compressive symptoms and multi-nodular goiters that is poised to start in Canada. The process begins by conducting a thorough assessment of the patient's condition followed by a discussion of the various treatment options. Here is a brief description.

Thyroid Arterial Embolization (TAE) is a non-invasive procedure performed by an Interventional Radiologist (IR) to reduce the flow of blood to the thyroid goiter and shrink the goiter. It is similar to the procedure used for removing heart arterial embolisms but in this case, you are actually doing the reverse: creating a partial embolism. A catheter is inserted in an artery in the arm and fished through to the thyroid artery where small particles are inserted to reduce blood flow. Fluoroscopy, a real-time X-ray imaging technique, allows interventional radiologists to visualize blood vessels and the location of the catheter during the embolization process. The result of this treatment leaves the patient euthyroid (patient does not become hypothyroid) and also avoids risks associated with thyroid surgery.

Our caller sent us the following link to a short TAE presentation given by Dr. Gary Tse at the UCLA Interventional Radiology Department.
See Thyroid Artery Embolization: New treatments for enlarged thyroid and thyroid nodules | UCLA Health - YouTube.

This treatment is very exciting! Not only is this a minimally invasive procedure with low risk but the treatment should be covered by health care!
We are planning on hosting an educational webinar on this treatment next fall.

NEW THYROID PATIENT GUIDE ON HYPOPARATHYROIDISM

What is Hypoparathyroidism?

Hypoparathyroidism is a condition where your body doesn't produce enough parathyroid hormone (PTH) or the hormone doesn't work properly. This hormone normally helps keep your calcium levels in balance. When it's missing or not working well, you can have low calcium levels, high phosphate levels, and sometimes too much calcium in your urine. These changes can affect many parts of your body, potentially causing problems with your kidneys, bones, heart, and nervous system.

What Causes Hypoparathyroidism?

Surgery, particularly thyroidectomy or parathyroidectomy, accounts for 75–80% of all hypoparathyroid cases. Non-surgical causes account for 20-25% of cases and include autoimmune conditions (i.e. autoimmune polyendocrine syndrome type 1), genetic syndromes (i.e. DiGeorge syndrome and autosomal dominant hypocalcaemia), infiltrative diseases (i.e. hemochromatosis and Wilson's disease), and magnesium disorders.

Although a high degree of thyroid surgeries indicates some parathyroid tissue in the surgical specimen, nearly all of these patients retain normal PTH and Calcium (Ca) levels and don't require treatment. The rate of permanent surgical hypoparathyroidism with total thyroidectomy is 1-2%, and rates among lobectomy patients are < 1%. While small fragments of parathyroid glands do come out, especially those embedded into the thyroid gland itself, it does not result in a problem for the patient most of the time.

How is it diagnosed?

Diagnosis relies on the confirmation of low calcium levels with inappropriately low or normal PTH levels. Other tests that are markers of the disease can include high serum phosphate, low 1,25-dihydroxyvitamin D, and elevated calcium levels in the urine. Patients who develop hypoparathyroidism after surgery can have transient or permanent disease.

What Complications Can It Cause?

The complications of hypoparathyroidism are wide-ranging and affect multiple system:

- **Kidneys**: Too much calcium in your urine can lead to kidney stones, calcium deposits in the kidneys, or even kidney damage.
- **Bones**: Dysregulation in how your bones remodel and repair can occur.
- Heart: Low calcium levels can lead to changes in heart rhythm (arrhythmias) and other heart-related issues such as cardiomyopathy.
- Nervous System: Low calcium can cause muscle cramps, spasms, seizures, and even changes in the brain such as calcifications in the basal ganglia.

Immune System: Calcium plays a role in how your immune cells work, so you might be more prone to infections.

How Is It Treated?

A. Conventional Therapy

The standard treatment is to take oral calcium and activated forms of vitamin D (i.e. calcitriol) to increase calcium levels in the body. The goal is to keep your blood calcium levels at the lower end of the normal range. This approach helps reduce risks like kidney stones. However, calcium and activated vitamin D supplements can sometimes lead to fluctuations in calcium levels, a need for many pills, high urinary calcium, increased phosphate levels and decreased quality of life.

B. PTH Replacement Therapy

PTH replacement offers a more physiological approach to managing hypoparathyroidism, reducing the need for calcium and vitamin D supplements and improving quality of life.

- PTH (1-34): This active fragment of PTH is effective to keep calcium levels normal, reduce urinary calcium levels, and may improve bone strength. However, because it doesn't last very long in the body, it must be given several times a day or through a continuous pump. PTH(1-34) is not an approved therapy for patients with hypoparathyroidism but is used off-label for this indication.
- PTH (1-84): With a longer half-life, this molecule last longer than PTH (1-34) and can be administered once daily. Clinical trials have shown its efficacy in reducing calcium and vitamin D supplementation requirements while maintaining normal calcium levels in the blood. Unfortunately, production of this form was being phased out globally since the end of 2024 due to manufacturing challenges.
- Palopegteriparatide (TransCon PTH): This is a newer treatment that links a fragment of PTH (1-34) to another molecule to extend its action profile over a longer time period. Recent studies have shown that it effectively keeps calcium levels normal, reduces urinary calcium, reduces phosphate levels, improves renal function and quality of

(Continued on page 13)

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life. Many patients using this treatment no longer need conventional therapies. The FDA approved this treatment for hypoparathyroidism in 2024.

C. Emerging Therapies:

Emerging treatments aim to address the limitations of conventional and current PTH replacement therapies:

- **Eneboparatide**: A long-acting PTH/PTHrP currently in advanced clinical trials. Early results from these studies are promising for both maintaining calcium balance and bone health.
- **Calcilytics** (Encaleret): These drugs modulate the calcium-sensing receptor to increase PTH secretion. They are also under investigation in advanced clinical trials at this time.

Summary

The management of hypoparathyroidism has evolved significantly, with more recent therapies offering improved outcomes compared to conventional treatment. While challenges remain in addressing complications and optimizing long-term care, ongoing research and innovation are paving the way for more effective, patient-centered solutions.

Written by Sarah Khan MD FRCPC, Staff Endocrinologist, Bone and Research Education Clinic, Oakville ON, January 2025.

THYROID FOUNDATION OF CANADA
MEMBERSHIP AND DONATION FORM

Name:

Address:

Telephone: Email Address:

MEMBERSHIP LEVEL

ONE YEAR:
☐ Regular $35 ☐ Senior $30 ☐ Family $45

TWO YEAR:
☐ Regular $60 ☐ Senior $50 ☐ Family $65

DONATION AMOUNT ☐ $25 ☐ $50 ☐ $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 K0H 1G0

Thank you for your support!

RESEARCH BRIEFS

The following Research Briefs are summaries from research articles prepared by Hanista Premachandran, TFC Director of Education and Research.

These summaries and others may be seen on our website at:
https://thyroid.ca/research/summaries/

Please refer back to our website for more prepared summaries in future.

Risk Factors for Thyroid Dysfunction in Pregnancy: An Individual Participant Data Meta-Analysis

Osinga et al. (2024)

Summary: This study describes the effectiveness of current risk factors used for targeted screening of gestational thyroid dysfunction. International guidelines recommend screening potential factors such as maternal age, BMI, parity, and thyroid antibodies. However, the discriminative ability of these factors are not well understood. This study used data from 65,559 participants to assess factors such as age, BMI, smoking status, parity, in vitro fertilization, twin pregnancy, and thyroid antibodies (TPOAb and TgAb) on overt and subclinical hypothyroidism and treatment indications (characterized as overt hypothyroidism, subclinical hypothyroidism with thyrotropin >10 mU/L, or subclinical hypothyroidism with TPOAb positivity). The results suggests that the currently recommended risk factors (age >30, BMI ≥40, and parity ≥2) yielded a detection rate of only 59% for overt and subclinical hypothyroidism, with an overall risk for these conditions varying less than 2% across different levels of age, BMI, and parity. However, thyroid antibody positivity (TPOAb and TgAb) was a significant risk factor, with higher risks of hypothyroidism and treatment indication for those testing positive for antibodies. Lastly, twin pregnancy was linked with a higher risk of overt hyperthyroidism. Overall, the authors question the clinical utility of current risk factors for targeted screening of gestational thyroid dysfunction, and they note that thyroid antibody testing appears to be a relevant indicator.

Read article: *https://www.liebertpub.com/doi/10.1089/thy.2023.0646*

Radioiodine Treatment of Patients with Graves 2 Hyperthyroidism

Lahooti et al. (2025)

Summary: This study discusses radioiodine (RAI) treatment for new-onset eye disease in patients with Graves' hyperthyroidism. While it has been shown that existing ophthalmopathy can worsen following RAI therapy, the development of new eye disease is rare. To assess the risk, researchers followed 31 patients (20 without eye symptoms and 11 with existing ophthalmopathy) before and after RAI treatment. Results showed that 5 out of 11 patients (38%) with pre-existing ophthalmopathy experienced worsening symptoms, especially among female smokers. Meanwhile, only 2 out of 20 patients (10%) without prior eye disease developed mild, new-onset ophthalmopathy post-treatment with no extraocular muscle involvement. Both groups showed an increase in serum TSH-receptor antibodies in 50% of cases, but no changes in orbital antibodies were noted. Overall, the authors suggest that Graves' ophthalmopathy may involve cross-reactive immune responses due to thyroid cell damage from RAI, leading to the release of antigens. Although the worsening of pre-existing disease can be managed with steroids, the rare occurrence of new disease highlights the need for further research on this topic to better treat the condition. The authors recommend informing all Graves' patients, especially female smokers, about the potential risk of eye disease following RAI to ensure informed consent.

UNDERSTANDING THYROID DISEASE AND HOW TO TAKE LEVOTHYROXINE

DONNA MINIELY M. ED.

As of the end of April 2025, a group of women in Brampton are more knowledgeable about Thyroid Disease and how it can affect them, their family members and their friends. After a live Zoom presentation on *Understanding Thyroid Disease*, they asked questions to ensure they understood the information. For example:

- What are the signs of post-partum depression?
- What should I expect after having a thyroid nodule biopsied?
- **Does it matter when and how I take my levothyroxine medication?**

The best people to consult about how to take your medication are pharmacists. They will tell you it's vital for absorption of the levothyroxine hormone to take it with water on an empty stomach 30-60 minutes prior to eating your breakfast, or 4 hours AFTER eating food. It's best to take it at the same time every day. Some people who wake up regularly in the middle of the night find it convenient to take the medication at that time.

For best absorption, do not take calcium (or a dairy product), iron, or other vitamins or supplements at the same time as you take your levothyroxine pill. Avoid eating or drinking – even juice or coffee – for an hour after taking your pill.

These instructions apply whether you are taking pure levothyroxine (labelled as Synthroid or Eltroxin) or desiccated thyroid extract (DTE) made from animal thyroid glands.

If you are using combination therapy and taking Cytomel (T3), speak to your doctor or pharmacist about when and how to take your medication as it may be absorbed differently.

Medication for hypothyroidism is easy to take but we need to provide the best conditions for its absorption so it can work effectively in our bodies.

If your organization would like to schedule a 45-minute presentation on *Understanding Thyroid Disease*, email us at *info@thyroid.ca*.

Donna Miniely has an M.A. and M.Ed. and is a former president of TFC. She is very knowledgeable of thyroid disease and has extensive experience with both adult education and remote learning. Donna's mother, Marjorie Miniely, started one of the first TFC chapters in London Ontario.

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 public awareness of **thyroid disease**
- Lend moral support to thyroid patients and their families
- Assist in fund raising for thyroid disease

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*

Become a TFC Volunteer!

Do you have skills and interests that you could share with TFC?

We'd love to talk to you!

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

Thyroid Awareness Dates

May 25th - World Thyroid Day

May 25-31 - International Thyroid Awareness Week

June 1-30 - Thyroid Month in Canada