

# Thyrobuletin

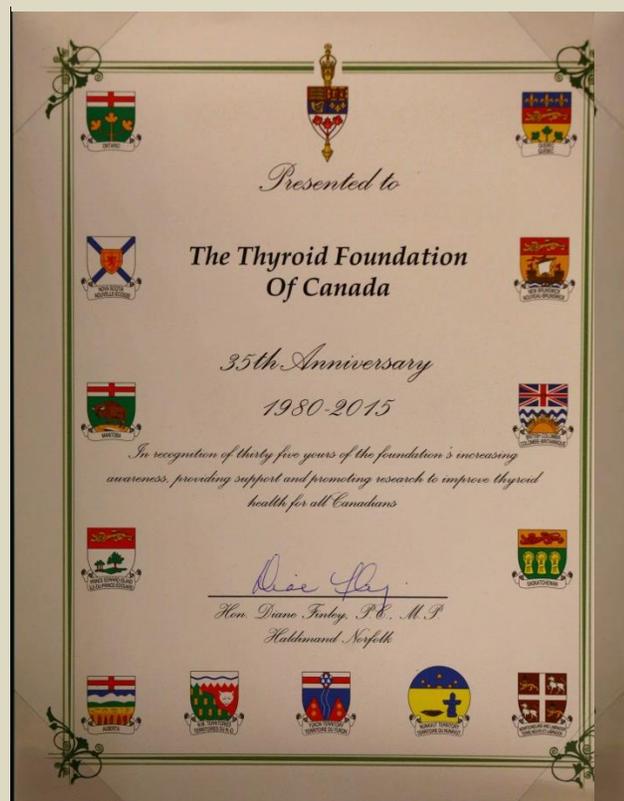


Autumn 2015

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- Highlights from the 15<sup>th</sup> International Thyroid Congress
- The Detection of Circulating Tumour DNA in Thyroid Disease
- Getting the Message Out: Thyroid Disease and Gluten-Related Disorders

## Celebrating 35 Years



Thyroid Foundation of Canada  
1980 – 2015





**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**

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*A message  
from the president*



*Un message de votre  
présidente*

Dear Readers and TFC members,

This year, the Thyroid Foundation of Canada proudly celebrates its 35<sup>th</sup> anniversary. At 35, humans are considered to be young adults, having attained some maturity and wisdom – often through overcoming adversity along the way. By that age, we have established our identity and we are doing our work in the world with the support and love of a network of family, friends and colleagues.

Similarly, the TFC has attained a level of maturity and wisdom. The Foundation is a trusted source of information for thyroid patients. We are clear on our identity (our mission and goals) and have a good network of support. The organization has overcome some adversity, but through that, has discovered its resilience, largely due to the support and resolve of the volunteers and advisors dedicated to the Foundation's work.

To maintain its vigour, the Foundation needs sustenance and input: sustenance in terms of donations, contributions and memberships; input from our advisors; and input from members such as ideas for articles and stories, suggestions, questions, and contributions of time and effort. I encourage you to make a generous donation as you renew your membership so that the Foundation can continue to provide information to thyroid patients and support further research.

The TFC will be seeking new Directors for the Board this spring. If you have a passion for the goals of the Thyroid Foundation, skills and previous Board experience, consider getting involved and making a difference!

On behalf of the Board, I wish you and your loved ones a happy and healthy holiday season.

Chers lecteurs et membres de la FCT:

Cette année, la Fondation canadienne de la Thyroïde est fière de célébrer son 35<sup>e</sup> anniversaire. À 35 ans, les humains sont considérés comme des jeunes adultes, ayant atteint une certaine maturité et sagesse - souvent en surmontant l'adversité au long du trajet. À cet âge, nous avons déjà établi notre identité et nous faisons notre travail dans le monde, avec le soutien et l'amour d'un réseau de la famille, amis et collègues.

De même, la FCT a atteint un niveau de maturité et de sagesse. La Fondation est une source fiable d'information pour les patients de la thyroïde. Nous sommes clairs sur notre identité (notre mission et nos buts) et nous avons un réseau de soutien solide. Notre organisation a surmonté l'adversité, mais à travers de cela, elle a aussi découvert sa résilience, en grande partie grâce à l'appui et la détermination des bénévoles et des conseillers dédiés au travail de la Fondation.

Pour maintenir sa vigueur, la Fondation a besoin de subsistance et participation: subsistance en termes de dons, contributions et adhésions; et, participation de nos conseillers; ainsi que la participation de nos conseillers; la contribution de nos membres en ce qu'il s'agit offrant des idées pour des articles et des histoires de leurs expériences, suggestions, questions et contributions de temps et ainsi que d'efforts. Je vous encourage à faire un don généreux lorsque vous renouvez votre adhésion pour que la Fondation puisse toujours continuer à fournir des informations aux patients de la thyroïde et de soutenir davantage la recherche médicale.

Le FCT est à la recherche de nouveaux administrateurs au Conseil ce printemps prochain. Si vous avez une passion pour les objectifs de la Fondation de la thyroïde, les compétences et l'expérience de travail chez le sein d'un Conseil, envisagez de participer et de marquer une différence!

Au nom du Conseil, je vous souhaite à vous et vos proches une saison des fêtes heureuse et en santé.

Donna Miniely



## Annual General Meeting 2015

### A Celebration year – 35<sup>th</sup> Anniversary

*Kingston, Ontario*

*Birthplace of Thyroid Foundation of Canada,  
1980 – 2015*

The Annual General Meeting 2015 marked the 35<sup>th</sup> anniversary of the Thyroid Foundation of Canada and was held in Kingston, Ontario, TFC’s birthplace. It was a time to go back to its roots and reflect on just what has happened in the last 35 years, since 1980 when Diana Meltzer Abramsky of Kingston took steps to do something to help thyroid patients all across the nation. Diana was motivated and inspired by those she met who had problems similar to herself. The desperation and anxiety she saw in others affected her immensely which gave her a reason to want to do something – there needed to be action. Others became aware of her passion and joined the quest to form into a group. The medical community along with sponsors came on board and it was then that the formation of the Thyroid Foundation of Canada became a reality.



TFC President Donna Miniely welcomes attendees to the 35<sup>th</sup> AGM

There was a lot to talk about and share in Kingston this past June. Lots of nostalgia for some of those who were there with Diana in the early days and shared her enthusiasm and helped to build the organization. It was very reflective of the early days of TFC in listening to Nathalie Gifford, Mary Salisbury, and Phyllis Mackey, some of the founders, as they recalled others and the work done by many in Kingston during the 1980s and further on. Being in Kingston gave the feeling we were revisiting history and the enthusiasm of continuing to do so well into the future. Along with sharing with some of the founding members we were glad to see some new faces and we look forward to sharing information on the various types of thyroid conditions with them.



Friends from the Kingston Area Chapter meet and new friendships are made.

With the many changes to the way we do things these days, and modernization bringing us into the digital world, we continue the work of Diana and the many others who set the foundation for TFC. We look forward to an exciting and productive future for thyroid patients through the Thyroid Foundation of Canada.



### A Presentation on Thyroid Disease, AGM 2015 Thyroid Health and the Thyroid Patient

We were very privileged and fortunate to have Dr. Josh Lakoff, Assistant Professor, Endocrinology and Metabolism at Queen’s University, Kingston, ON, share his knowledge and awareness of Thyroid Health during our AGM 2015 in Kingston. Being fairly new to that area of medicine, Dr. Lakoff was able to share some of the latest findings. This helped patients understand what they are experiencing with their condition and gave them a better knowledge of what thyroid disease is. Those attending were able to gain valuable



information not only on their own condition but the condition of family members and others who may be suffering from a thyroid condition.

We look forward to future contact with Dr. Lakoff. Thank you to Dr. Lakoff and to Dr. Robyn Houlden from Queen’s University for suggesting Dr. Lakoff to do the presentation.

## Celebrating and Remembering

The 2015 AGM was a time of Celebration and a time of Remembering. Sharing in the journey and accomplishments of the past 35 years was very humbling and rewarding for a number of those attending. As we celebrated the various activities and events from 1980–2015, we reflected on those who were a big part of making it all happen. Nathalie Gifford and Mary Salsbury were there with Diana at the beginning of the Thyroid Foundation of Canada as were many others.



The late Margaret Burdsall was also there at the beginning so we were delighted to have Margaret’s two daughters, Anne Lombard and Liz Ellwood, present at the Banquet. They assisted in the cutting of the cake with Nathalie and Mary. Margaret’s presence was definitely felt by many of us that evening as her contribution was of great significance and recognized over the years.

Friends and family of Margaret Burdsall do the honours of cutting the 35<sup>th</sup> anniversary cake.

## More AGM Highlights

Messages of congratulations on TFC’s 35<sup>th</sup> anniversary were received from Diane Finley, MP; Prime Minister Stephen Harper; and Rona Ambrose, Minister of Health.

Tributes were given to TFC’s Founder Diana Abramsky and the late Margaret Burdsall, a long-time member of TFC from Kingston, ON who passed away this past year.



Director Gabriela Albarracin read congratulations from Rona Ambrose, Minister of Health



Town Crier Chris Whyman

We took a break from the meeting to watch as Town Crier Chris Whyman proclaimed TFC’s 35<sup>th</sup> Anniversary in Kingston’s Market Square.

Prashanth Dinavahi, Product Manager, Mylan EPD, spoke about the initiatives Mylan has been working on: *Pharmacist Continuing Education* certification and *Thyroid Health Days* held in pharmacies across Canada. Mr. Dinavahi accepted a Patient Care Award on behalf of Mylan.



Ashok Bhaseen (left) presents Patient Care award to Prashanth Dinavahi



## Farewell to Ashok

At the 2015 AGM, after three terms, Ashok Bhaseen stepped down from the Board of Directors of the Thyroid Foundation. Ashok’s work with non-profit organizations began back in India where, in 1978, as President of the Rotary Club’s Junior Wing, he opened a Mission of Charities for Mother Teresa. Ashok likes to make a difference in people’s lives, so, early in his career as a pharmacist, he made sure that people in Indian villages had basic first aid medicines.

Ashok joined the TFC Board in 2007, and became President in 2008, just in time to steady the course for the Foundation as it faced huge challenges. Fortunately, one of Ashok’s favourite sayings is: “Opportunities come in the form of problems.”

During his tenure as President, Ashok helped the Thyroid Foundation survive, taking it from a deficit position to the healthier financial position it enjoys today. Anyone who knows Ashok knows that he goes above and beyond to care

for others. He never looks for personal awards; he does the work out of his passion for making people’s lives better and he credits the people around him in those toughest years:

Barb Cobbe, Mabel Miller, Cathy Fey, Marjorie Miniely and Philip Morrissey, for the Foundation’s success at that time.



Another of Ashok’s favourite sayings is: “Tough times never last, but tough people do.” Teamwork is very important to him and he enjoys cultivating new leadership as it is vital for the organization to flourish. Ashok found the work with TFC satisfying, saying it made him stronger in his personal and professional life. Ashok will be continuing on as the President of Thyroid Federation International and is on the Board of several other organizations including the Canadian Skin Cancer Foundation and Graves Disease Foundation.

We’ll miss you, Ashok, and we wish you all the best!

## Message to Thyroid Federation International from Thyroid Foundation of Canada



Congratulations to the Thyroid Federation International on its 20th anniversary! At our AGM in June 2015, the Thyroid Foundation of Canada (TFC) celebrated its 35th anniversary and as part of looking back over our history, we viewed pictures from the 1995 AGM in Toronto where the TFI was launched.

Several members at the 2015 AGM had attended the ‘birth’ of the TFI, which was the realization of one of Diana Meltzer Abramsky’s wishes: “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.”

Diana founded the Thyroid Foundation in Canada, the first thyroid foundation in the world. Her wishes, which can be viewed at [http://www.thyroid.ca/diana's\\_wishes.php](http://www.thyroid.ca/diana's_wishes.php), continue

to provide direction for TFC’s efforts and perhaps resonate for other member organizations of TFI.

What a delight to see that TFI is thriving and growing bigger each year, demonstrating that word is getting out around the world about the symptoms and challenges of thyroid disease and the treatments for various conditions.

This past year, TFC partnered with Abbott Pharmaceuticals (now Mylan) to undertake two initiatives. The first was to host accredited training for pharmacists on the [www.thyroid.ca](http://www.thyroid.ca) website. Entitled “Thyroid Disorders – A Pharmacy Approach to Managing Patients’ Thyroid Health”, more than 200 pharmacists had completed the training within the first 6 months.

*(continued on page 9)*



## A Tribute to Diana

Diana Meltzer Abramsky, C.M. BA.  
1915 - 2000



A long time ago, a lady from Kingston, Ontario, Canada had a dream, or should I say she saw a need, a need we're all very familiar with and it all started because she realized there were no answers to her own health situation being Graves' Disease, a thyroid condition, and for years was led to believe her problem was psychosomatic! Diana had a dream that led to a mission.

A turning point for Diana was when she was sitting and waiting for an appointment at a thyroid clinic in Kingston, Ontario. Sitting next to Diana was a young girl who seemed to be very upset about a similar condition. So in 1980 this led to Diana forming the Thyroid Foundation of Canada. One of her key supporters was an Endocrinologist, Dr. Jack Wall who was attending to her regarding the issues she had with her thyroid problem.

### Some information around the forming of Thyroid Foundation of Canada

Along with Diana were: Mary Salsbury, Dr. Laurence Wilson, Phyllis (Hannah) Mackey, Walter Viner, QC, Dr. Jack Wall, Ralph Abramsky, Evelyn & Len Freeman, Nathalie & Bob Gifford, George & Carol Wright, Margaret Burdsall, Jack Tarantello, Sherry Stayer and The Frontenac County Board of Education who provided volunteer space for meetings.

Initially, the first six Chapters established were: Kingston, Ontario; Vancouver, British Columbia; Ottawa, Toronto, and Kitchener-Waterloo in Ontario; and Edmonton, Alberta. Over the next few years, the organization had grown to 22 chapters from coast to coast across Canada.

As well, similar organizations were being established all over the world – the US, UK, Europe, Asia, and South America.

In 1990 during the International Thyroid Congress in Toronto, an international patient organization was formed which is now known worldwide as Thyroid Federation International and Diana was there for that wonderful occasion.

Here we are 35 years after Diana's quest to do something about the lack of information on thyroid disease for thyroid patients.

I would now like to share with you some of Diana's words about the organization from a speech she gave in June 1987

which puts it all in perspective. She titled it "Accepting the Challenge". Diana wrote:

*"What happy memories we have of early beginnings and continuing milestones in our progress.*

*"There is so much to be thankful for ...That helping others has become a way of life for members of the Foundation as they help to spread the knowledge gained across Canada and the world.*

*"We are enjoying our status as a Thyroid Foundation on the world stage as chartered members of Thyroid Federation International. We take pride in the fact it all started in Kingston, ON, Canada.*

*"We are thankful that we have made and will continue to make a difference in our own lives and lives of others. [Diana stated] For me personally I am thankful that I have lived to see my dream come true of a world-wide Thyroid Foundation come to pass."*

My own feelings are we should never fail to be indebted to Diana and the insight, the fortitude, the efforts and the accomplishments that have been realized from her quest. I only wish she could be here today so we could show her our appreciation. God Bless her for her enthusiasm and fortitude.

The Thyroid Foundation has come a long way, climbed over many hurdles, fought many battles, undertaken many endeavors, been fortunate enough to have many dedicated people who have and still want to continue the mission for better quality of life for thyroid patients and their families. Thyroid disease is a family affair and impacts not only the patient but families as well. We should never lose sight of that.

Congratulations to The Thyroid Foundation of Canada on celebrating the 35<sup>th</sup> Anniversary of its founding.

Mabel Miller





# Light a Tree for Thyroid



**with a Donation!**

You can help the **Thyroid Foundation of Canada** to help you or someone close to you.

**Your donation will help greatly towards Thyroid Education, Support and Research  
For each \$20.00 donation we'll put a light on the tree for you!!**

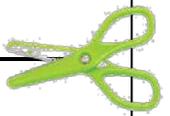
To make a donation - go to our website - [www.thyroid.ca](http://www.thyroid.ca)  
and follow the link - **"Join/Donations"** - Or you can send your donation  
using the form below. Or donate through [CanadaHelps.org](http://CanadaHelps.org)

Please make your donation payable to: "Thyroid Foundation of Canada"  
An income tax receipt will be provided for donations of \$20.00 or more.

If anyone in your family has had thyroid disease, then chances are  
others may have problems as well. Thyroid disease can affect anyone at any age.

Wishing you Safe and Happy Holidays!!

*PS - Check our website to see our tree and the lights that are added!!!*



## Thyroid Foundation of Canada – Light a Tree – Donation Information:

Name: \_\_\_\_\_ Email address: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

Amount of donation:  \$20  \$40  \$60  Other  Cheque included or

Credit Card:  Visa  Master Card.

Card # \_\_\_\_\_ Expiry Date: \_\_\_\_\_

Name on card: Same as above \_\_\_\_\_ or \_\_\_\_\_

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



## Thyroid Hormone Replacement: Principles and Practice

Gerald JM Tevaarwerk BA, MD, FRCPC, Cert. Endocrinology

The absorption of levothyroxine (Synthroid<sup>®</sup>, Eltroxin<sup>®</sup>, T4) varies from person to person and many medications and foods interfere with it.<sup>1,2</sup> ***It should be taken on a stomach that has been empty for 4 hours, with some water, and no other medications, supplements or food for 1 hour thereafter.*** All thyroid preparations should be taken at the same time.

Thyroxine (T4) is an *inactive* prohormone that is *converted* in the body to the *active* hormone triiodothyronine (T3). Normally, an average of 80% of T3 is derived from T4 conversion (*activation*) and 20% comes directly from the thyroid gland. When taking levothyroxine all the T3 comes from the activation of T4. This, by the *law of mass action*, means that *the T4 level must be approximately 25% higher* than in normal individuals to attain the same T3 level. The result is that the ratio of T4/T3, normally 3 to 1, on replacement with levothyroxine averages 4 to 1.<sup>3,4</sup>

Various organs in the body convert T4 to T3 at different rates, using enzymes called *deiodinases*.<sup>3</sup> The T3 in the thyrotrope cells of the pituitary suppresses TSH production in those cells. Other organs may have less active conversion, resulting in them still being ‘hypothyroid’ when the pituitary already gets enough T3 to reduce the TSH to normal.<sup>4</sup> Several decades ago the *American* and *European Thyroid Associations* adopted the position that TSH levels are the best way to monitor thyroid replacement therapy. However, new evidence suggests, “*a combination of T3 and T4 levels may be better indicators of the adequacy of replacement.*”<sup>4,5</sup> A large study from Bristol, England, found that 26% (1 in 4) patients on treatment with T4 alone continued to have hypothyroid symptoms in spite of normal TSH levels and that those patients had lower T3 levels than those without residual hypothyroid symptoms<sup>6</sup>. Subsequently, the same investigators found that patients with lower T3 levels had *genetic variations* in deiodinase enzymes 1 or 2.<sup>7,8</sup> These

findings may explain the residual hypothyroid symptoms frequently found in clinical practice<sup>9</sup> and the results from trials in Lithuania in 1999<sup>10</sup> and Denmark in 2009<sup>11</sup> and 2013,<sup>12</sup> that adding liothyronine improved brain function, and endogenous depression and/or bipolar disorders in patients who also had hypothyroidism. Furthermore, hypothyroid patients on T4 alone continued to have several biochemical abnormalities that could only be corrected by adding T3 to the T4 treatment.<sup>12</sup> A recent publication pointed to both deiodinase 1 and 2 as possible *primary* causes of impaired generation of T3 from T4.<sup>13</sup> These findings have renewed the interest in using combinations of T4 and T3. However, plain liothyronine (Cytomel<sup>®</sup>) is too rapidly absorbed, resulting in peaks and troughs. To attain the average T3 levels as found in normal individuals using T4 replacement alone requires T4 levels to be raised to or above the upper limit of normal, thereby possibly causing acceleration of the normal bone loss of aging and increasing the risk of atrial fibrillation.<sup>14</sup> On the other hand inadequate treatment of hypothyroidism is associated with an increased risk of heart disease and strokes.<sup>15,16</sup> An alternative approach might be to aim for the T4 and T3 levels most commonly found in healthy normal individuals, i.e., *mid-normal concentrations*, using ‘extended’ or ‘slow’ release preparations of liothyronine (SR-T3), as was recommended as long ago as 1999.<sup>17,18</sup> In 2004 that became possible when Hennemann *et al*, in a *Proof of Principle* experiment on 15 patients, demonstrated that a combination of thyroxine *plus* SR-T3 improved the T4 and T3 values and the T4/T3 ratio without causing excessive peaks or valleys of T3.<sup>19</sup> No attempt was made to evaluate the clinical effects. Some patients using a combination of levothyroxine *plus* SR-T3 titrated to mid-normal T4 and T3 concentrations have been shown to benefit markedly.<sup>9</sup> Although promising, a blinded, randomized controlled trial is needed to obtain stronger evidence before this approach can be more generally recommended.



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Look for more information on this subject in our next issue of *Thyrobuletin* (Spring 2016).

Do you have questions? Send them to: **Thyroid Foundation of Canada, P.O. Box 298, Bath, ON K0H 1G0**

## Message to Thyroid Federation International (continued from page 5)

The second initiative was to hold Thyroid Health Days in pharmacies across the country where a nurse was available to discuss a thyroid assessment questionnaire with thyroid patients. These Health Days were held in over 80 pharmacies during the first 6 months.

TFC is funding research at the London Health Science Centre in London Ontario into the *Detection of Circulating Tumour DNA in Thyroid Disease*. We hope that one day, the number of indeterminate results for thyroid nodule biopsies can be reduced with the help of a simple blood test.

The TFC's website continues to be very popular, attracting 120,000 visitors each month from around the world. Watch for enhancements to this website over the coming year!

Once again, we send our congratulations to TFI on its 20th anniversary. May TFI and its member organizations continue to flourish in order to reach out and help all thyroid patients around the world.

Donna Miniely, President



Thyroid Federation International aims to work for the benefit of those affected by thyroid disorders throughout the world. There are currently 23 member groups in 20 countries around the globe. For more information, visit [www.thyroid-fed.org](http://www.thyroid-fed.org)



## Highlights from the 15<sup>th</sup> International Thyroid Congress

By Deric Morrison MD, FRCPC, TFC Medical Advisor



I was fortunate to have the opportunity to attend the 15<sup>th</sup> International Thyroid Congress (ITC) October 18-23, 2015 in Orlando, Florida. The ITC is a collaborative meeting, held every 5 years, of the four world thyroid associations: this year's host the American Thyroid Association (ATA), the Asia-Oceania Thyroid Association (AOTA), the European Thyroid Association (ETA) and the Latin American Thyroid Society (LATS). This meeting is attended by world renowned clinical thyroidologists, researchers, educators and scientists.

The conference opened with an excellent review session including presentations from experts in immunology, thyroid cancer and clinical thyroidology. It was entitled "Thyroid Research – Highlights from the Last Decade." The next five days were filled with high quality plenary lectures, symposia, discussions, and debates on clinical and research issues related to thyroid dysfunction and thyroid cancer. In addition, there were a large number of oral abstracts and poster presentations highlighting cutting edge basic science and clinical research related to thyroid disorders. One such study addressed the question of whether treatment of hypothyroidism with a combination of T4/T3 would improve patient wellbeing compared with standard levothyroxine therapy. In this randomized and blinded crossover study no benefits were seen with the T4/T3 combination, but neither were there any safety concerns. This reinforces that the current standard of care of treatment with T4 is the usual appropriate approach, with combination or T3 treatment reserved for rare situations. However, questions remain about whether improved T3 preparations, or if selecting particular patients (e.g. with low Free T3), for combination therapy could show benefit. Hopefully further research will address these questions.

Just prior to the ITC, the ATA released the new 2015 American Thyroid Association Management Guidelines for Adult Patients with Thyroid Nodules and Differentiated (Papillary and Follicular) Thyroid Cancer. A number of ITC sessions related to these comprehensive guidelines that aim

to address the challenges of identifying the minority of high risk differentiated thyroid cancer patients so that they can benefit from more aggressive treatment and monitoring, while minimizing potential harm from overtreatment to the majority, low risk, differentiated thyroid cancer patients. To this end, these guidelines suggest decreasing the amount of low risk thyroid nodules that are biopsied, treating more low risk thyroid cancers with removal of one thyroid lobe rather than the whole thyroid, and recommending that most low risk patients not be treated with radioactive iodine.

Another exciting development in the diagnosis of thyroid nodules is the use of molecular testing of thyroid nodule biopsy specimens to help predict the risk of malignancy in biopsies with indeterminate pathology diagnoses. These molecular tests are not widely available in Canada, but are used in some parts of the United States and Europe. While these tests hold promise for decreasing the need for thyroid surgery to diagnose indeterminate nodules, questions remain about their accuracy over the long term, performance in real world rather than research trial settings and cost effectiveness.

This is an exciting time with new thyroid cancer guidelines and research developments that will help to improve the care of patients with thyroid dysfunction and thyroid cancer. The ITC was an excellent opportunity to discuss thyroidology with colleagues and world renowned experts in the field, as well as learn about novel thyroid research accomplishments.

### References:

2015 International Thyroid Congress and Annual Meeting of the American Thyroid Association; Orlando, Florida. Posters 272, 822, 829, 838. Abstract 7. Presented October 19-22, 2015.

2015 American Thyroid Association Management Guidelines for Adult Patients with Thyroid Nodules and Differentiated Thyroid Cancer. Haugen, B., Alexander, E., et al., DOI: 10.1089/ thy. 2015.0020



## The Detection of Circulating Tumour DNA in Thyroid Disease

Anthony Nichols, MD, Chair, Head and Neck Cancer Disease Site Team, London Regional Cancer Program  
Head and Neck Cancer Surgeon, LHSC

Thyroid nodules are extremely common, with five per cent of the population having palpable nodules and up to 50 per cent of the population having nodules that can be detected on ultrasounds. Nodules are up to five times more common in women.

Despite the common occurrence of nodules, only five to 10 per cent of them harbour cancer. The standard evaluation of patients with thyroid nodules includes an ultrasound and needle biopsy. If the ultrasound characteristics are not worrisome and the needle biopsy is benign, nodules can be observed, as the chance of malignancy is low. Conversely, if the needle biopsy is conclusive for malignancy then surgery is indicated, as the nodule is almost certainly cancerous.

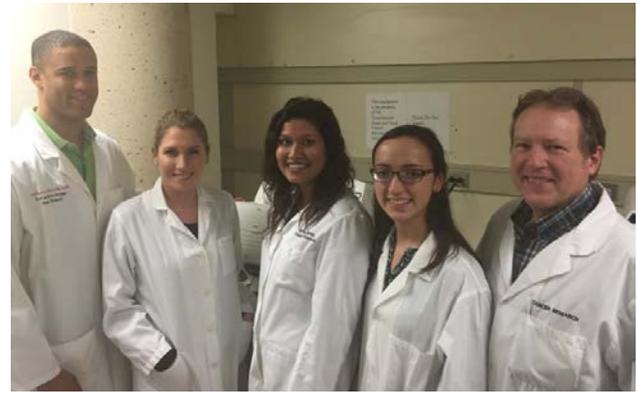
Although the standard work-up clearly directs patient care in this situation, approximately 50 per cent of the time needle biopsies and ultrasound results can be indeterminate and provide only a relative risk of malignancy.

Most commonly, approximately 25 per cent of needle biopsies are reported as follicular lesions of undetermined significance (FLUS) or follicular neoplasms that have 10 per cent and 30 per cent chances, respectively, of being malignant.

Typically, patients with these fine needle biopsy results undergo diagnostic surgery, with only a small proportion found to have cancer. Although thyroid surgery is generally safe, there are still risks including bleeding, scarring, pain, nerve injury, voice alteration and calcium issues. Thus, many patients undergo unnecessary surgery and suffer side effects that could potentially be avoided if improved diagnostics were available to better differentiate benign from cancerous nodules.

In addition to diagnostic challenges, patients that are conclusively diagnosed with thyroid cancer on final pathology need to be monitored for recurrence. This is typically done with ultrasounds as well as thyroglobulin levels (a protein secreted in thyroid tissue); however, neither is perfectly accurate for picking up recurrences early.

Thyroglobulin specifically can be undetectable in the blood stream even in the 10 per cent of patients who still have their



Members of the Thyroid Cancer Translational Research Team (from left): Anthony Nichols, MD; Morgan Black, MSc; Nicole Pinto, PhD candidate; Kara Ruicci, MD/PhD candidate; and John Barrett, PhD.

thyroid in place. Ideally, a non-invasive blood test could assist with diagnosis as well as patient follow-up.

### **The background on our research project:**

All cells contain DNA (genetic material) that can potentially be released into the blood stream when cells die. Cancer cells harbour genetic changes (mutations) that can enter the blood stream and be detected, as this mutant DNA has a different sequence than the DNA from normal tissue. This DNA enters the bloodstream at a higher rate than in normal tissue, as a significant subset of cells die in the rapidly growing tumour as part of the tumour outgrows its blood supply (tumour necrosis).

In many cancer types, scientists have been able to identify this mutant DNA, which is known as circulating tumour DNA (ctDNA). Interestingly, ctDNA appears to be highly correlated with disease status, with ctDNA levels dropping after successful therapy and rising at the time of disease relapse.

There are preliminary studies of the detection of ctDNA in thyroid cancer hinting at its potential as a diagnostic and therapeutic tool. Most of these studies have been done using a real-time polymerase chain reaction (PCR) technique to amplify and detect DNA.

We're aiming to refine the detection of ctDNA in the evaluation of thyroid nodules and to work toward integrating this technology into clinical care. Our initial research,



presented below, uses the real-time PCR technique; however, we're transitioning to a genetic sequencing machine called the ion Torrent, which we believe will give more accurate and reproducible results.

### Progress to date:

- A graduate student and a medical student have been specifically recruited for this project. Two research associates recruit patients in the clinic and facilitate blood-sample collection. A pathologist and a pathology resident are coordinating the retrieval of the thyroid tumour specimens.
- Ethics approval for this study has been obtained from Western University. More than 120 patients with thyroid nodules scheduled to undergo surgery have given their consent, and pre-operative blood samples have been obtained. Ten patients have declined the post-operative blood draws (as thyroid patients often have multiple post-operative blood tests).

A total of 76 patients have had both pre- and post-operative blood work. We've obtained the final pathology results from all patients as well as tumour samples from the primary thyroid tumours whether benign or malignant.

- The molecular testing completed thus far includes testing pre-operative blood samples from the first 62 patients for the BRAF mutation by real-time PCR. Pre- and post-operative blood samples as well as formalin-fixed samples from the index thyroid nodule were also tested in 38 patients.

We've compared the pre- and post-operative blood work and discovered that the ctDNA levels became undetectable post-operatively in all but one case in which complete tumour removal wasn't possible - suggesting its utility as a tumour marker. In addition, we found that the presence of ctDNA was associated with more aggressive tumours (i.e. larger tumours with extension outside the thyroid).

Surprisingly, we detected the mutant BRAF in the blood of two patients who had no cancer in their thyroid. This could be happening because the mutation is not exclusive to thyroid cancer (i.e. some patients have other

cancers that are giving this positive result), or because a small subset of benign nodules (five to 10 per cent) harbour this mutation and represent pre-malignant lesions.

### Future directions:

The Department of Otolaryngology has purchased an ion Torrent sequencer, which can test for a variety of mutations (not just BRAF). The advantage of this system is that it can test multiple genes all in the same run, and it reads each gene many times (approximately 20,000) so we can quantify the relative amount of mutated DNA to normal DNA in a quantitative "digital" fashion.

We believe this technique will be markedly more accurate than the real-time PCR. We've already purchased and received a custom-designed "thyroid panel" to carry this out. Our graduate student Dr. Krupal Patel will be running this assay over the months to come.

In addition, we've leveraged our samples and obtained an industry grant from Thermo Fisher Scientific to also test our samples on their proprietary digital PCR platform. This will provide us with another technique to compare our ctDNA levels to determine which methodology is the most cost-effective, sensitive and specific.

### Impact and significance:

Although our preliminary results do not clearly distinguish between benign and cancerous tumours, the addition of more genes may resolve this shortcoming.

Our results to date indicate that this technique may be highly valuable for identifying patients with aggressive disease as well as for monitoring for relapse after surgery. If validated, this technology can help us to offer highly personalized care for patients suffering with thyroid disease.

Thank you for your generosity in supporting the London Health Sciences Centre (LHSC) research project *The Detection of Circulating Tumour DNA in Thyroid Disease*. We're pleased to provide this impact report updating you on the research progress made possible through your generosity!

Note: This year, the TFC donated \$32,883.55 to this project, funds that were raised over several years by the *Touch of Spring* Fashion Show in London ON.



## Why the Detection of Circulating Tumour DNA research matters

Thyroid nodules are very common and only 5-10% are malignant, so it is important to be able to distinguish between the serious ones and the benign nodules.

In 2014, a neck ultrasound “accidentally” discovered that I have a thyroid nodule. A decision was made to monitor it for a year. This past summer, after another ultrasound revealed that the nodule had grown slightly and another had appeared, a biopsy was scheduled and I was given the opportunity to take part in a randomized study which would either do a fine needle aspiration (FNA) or a biopsy. The radiologist attempted a FNA but, because the nodule was calcified and hard as a rock, the fine needle couldn’t puncture it to gather a tissue sample. The radiologist then elected not to do a biopsy because the nodule is very close to the carotid artery and he didn’t feel he would have sufficient control of the knife after puncturing the nodule’s hard surface (if indeed he was able to do so!). Thus, the results of the attempted biopsy came back “unsatisfactory”.

Even though some of the nodule characteristics are somewhat worrisome, the solution, for now, is to wait and do another ultrasound next year to see if the nodule has continued to grow (or shrink as sometimes happens), developed different characteristics, spread to the lymph nodes (hopefully not!), or if other nodules have appeared.

A simple blood test that could determine if nodule(s) are malignant or not will potentially save patients a lot of anxiety and lost time - taken for testing and appointments. An effective test could also spare patients the risks of unnecessary surgery. Imagine the savings in health care costs if nodule testing and follow up could be focused on the 5-10% of thyroid nodules that are malignant and require surgery! We wish Dr. Nichols’ team all the best with this research and anxiously look forward to their results!

Donna Miniely





## LEVOTHYROXINE FAQ



1. *When is the best time to take my levothyroxine dose?*

*It is good to take levothyroxine on an empty stomach 30 to 60 minutes before breakfast with a glass of water. As an alternative, you may take your levothyroxine at bedtime about 4 hours after supper when your stomach is empty. It is very important that you take your levothyroxine at the same time each day in the same way.*

2. *What foods should I avoid while taking levothyroxine?*

*There are some types of foods that may lower the effectiveness of levothyroxine. These foods include dairy products, calcium fortified fruit juices and dietary fibre. You may still have these types of food but it is best to separate them from your levothyroxine by about 4 hours.*

3. *What happens if I take my levothyroxine with other medications?*

*Medications like antacids, iron pills, multivitamin with minerals and bisphosphonates can interfere with the absorption of levothyroxine. These medications should be taken separately from levothyroxine by about 4 hours. Check with your pharmacist about the medications you are taking.*

4. *Is there a difference between brands of levothyroxine?*

*Health Canada requires that a change in brands of levothyroxine warrants a re-testing of TSH (thyroid stimulating hormone) levels followed by a dose titration if necessary. Your pharmacist will let you know if you are getting a different brand of levothyroxine and will be happy to discuss any concerns you may have.*

5. *When should I see my doctor?*

*Check with your doctor if there has been a change in your brand or routine of dosing of your levothyroxine. Also, let your doctor know if you experience any symptoms of elevated thyroid hormone such as heart palpitations, nervousness/irritability, tremor or symptoms of low thyroid hormone such as fatigue, depressed mood, lethargy or weight gain.*

© Ijenna Osakwe BPharm APA CDE CTH



## Getting the Message Out: Thyroid Disease and Gluten-Related Disorders

Joan Lister, President and CEO of HealthComm Inc.



Celiac disease is an inherited disorder. It is a chronic small intestinal immune-mediated condition that is caused by exposure to dietary gluten such as wheat and rye, and to a lesser extent in barley and oats. In people who have this disease, gluten causes changes in the intestine that impair their ability to digest and absorb foods.

As is sometimes the case with autoimmune diseases, people who have one such disease may develop another. For example, a person with celiac disease may develop rheumatoid arthritis, diabetes type 1, psoriasis or autoimmune hypothyroidism or any other autoimmune disorder.

For many years, celiac disease was considered to be a children's disease. Among adults, its prevalence was low.

In 2011, at the International Coeliac Disease Symposium in Oslo, gastroenterologists reported seeing the disease increasingly in adults. It was agreed that research was needed and a committee was formed for the purpose of developing definitions for celiac disease and related terms.

A key result of that committee's deliberations was the recommendation that the umbrella term for all diseases triggered by gluten in which celiac disease has been excluded would be "non-coeliac gluten-related disorders".

What caught our collective eye, as health communicators, was the possibility of a link between immune-mediated conditions such as auto-immune hypothyroidism and celiac disease, and non-coeliac gluten-related disorders.

Another reason it interested us was the emergence in

2012 of the wave of Canadians claiming to be sensitive to gluten. By 2013, almost everyone knew at least one person who described themselves as "gluten-sensitive".

Reports on two clinical studies – one in the United States, the other in Italy – established the link between celiac disease and auto-immune thyroid disease. In the general population, approximately one in 14 adults develops thyroid disease and one in 100 develops celiac disease.

In contrast, according to those studies, people diagnosed with celiac disease are three times more likely than the general population to have a thyroid disorder. And the thyroid disorder they are most likely to have is hypothyroidism.

Results of the clinical research that was agreed upon at the 2011 Oslo conference -- and for which the terms of reference were developed -- do not appear to have been published yet.

In the absence of Canadian clinical data, it was decided to conduct a national survey of Canadian adults. The survey referenced only celiac disease and gluten-sensitivity. The term "gluten-sensitivity" was used in its broadest sense and not restricted to "non-coeliac gluten-related disorders".

Results showed that:

- 19 percent of respondents avoid gluten;
- Three percent had been medically diagnosed as gluten-sensitive, and
- One percent had been medically diagnosed with celiac disease, which is consistent with U.S. and European prevalence data.



Drilling down into that data, we found that:

- Of the respondents who said they had been medically diagnosed with gluten-sensitivity, 16 percent reported also having been medically diagnosed with thyroid disease.
- Among respondents who said they had been medically diagnosed with either celiac disease or gluten-sensitivity, 10 percent said they also had been medically diagnosed with thyroid disease.

Symptoms of the two most common thyroid diseases -- hypothyroidism and hyperthyroidism -- are so general that patients often do not think of them as symptoms. For that reason, it was decided to develop awareness of the link between thyroid disease and celiac disease, a possible link with other gluten-related disorders, and to educate patients and the public as to the symptoms of thyroid disease.

In educating Canadians about thyroid disease, our communications objectives are threefold:

- Create an understanding of the role, importance and location of the thyroid gland.
- Develop awareness of the two most common forms of thyroid disease, the signs, symptoms and risk factors associated with each, and the consequences of failing to treat thyroid disease.
- Promote awareness of the Thyroid Foundation of Canada as an information resource and source of support.

The first and third objectives are relatively easy to achieve. The challenge lies in the second. Why? Because symptoms may occur in such disparate clusters that they often are not connected to a disease.

Most of us might not perceive a relationship between, for example, hair loss, constipation and sensitivity to cold. Or unexplained weight change, disturbed sleep and vision changes.

Much of our work, therefore, centres on educating patients about the symptoms of thyroid disease and the importance of noting them in order to provide their physicians with as much relevant information as possible.

In order to spread the word widely, we enlist the mass media. Reporters and program hosts require the expertise of specialist physicians and almost always like to hear about the personal journeys of patients living with thyroid disease.

Over the past year, HealthComm's work with media on building awareness of the link between thyroid disease and celiac disease, and its possible link with non-coeliac gluten-related disorders has reached audiences of more than nine million Canadians.

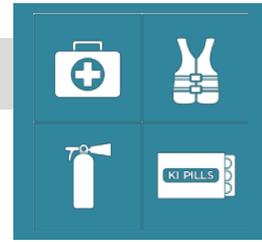
*Joan Lister is President & CEO of HealthComm Inc., a communications company specializing in health. HealthComm is based in Toronto.*

***Thanks to our partners and supporters:***





# Nuclear Energy and Thyroid Safety



The Canadian Nuclear Safety Commission (CNSC) — the federal agency that monitors the safe operation of nuclear stations — now requires that all homes and businesses within 10 km of a nuclear power station receive a supply of potassium iodide (KI) pills. The pills have been available free of charge at select pharmacies, but will now be sent by mail due to increased safety standards.

In the very unlikely event of a nuclear emergency and a release of radioactive iodine to the public, KI pills will help prevent the development of thyroid cancer, and are especially effective at safeguarding children's thyroid glands. It is important for each household to have a supply of these pills because they are most effective if taken just before or soon after exposure to radioactive iodine.

The distribution of KI pills is not due to any change in the risk of a nuclear emergency and is not meant to cause alarm. We believe that staying safe means being prepared, even for the most unlikely of events.

Courtesy Ontario Power Generation: [www.opg.com/](http://www.opg.com/)  
Canadian Nuclear Safety Commission: <http://nuclearsafety.gc.ca/eng/>  
(Government of Canada)

## Important Dates in 2016

Be sure to check back at <a href="http://www.thyroid.ca">www.thyroid.ca</a> for coming events in the New Year!		
April 10-16		National Volunteer Week - Thank a Volunteer!
May 25-31		International Thyroid Awareness Week The topic for 2016 is "Thyroid Disorders in Children"
May 25		World Thyroid Day
June 1-30		June is Thyroid Month in Canada!
June 11		TFC Annual General Meeting, Toronto ON



# News and Events



## CALGARY

On September 16, 2015, Ijenna Osakwe, B Pharm, a pharmacist educator at the Crowfoot Calgary Co-op Store gave a presentation on "Thyroid Disease: Managing Your Medications". We thank the Co-op for the use of their community room and Ijenna for her informative presentation. As part of her presentation, she contributed the **Levothyroxine FAQ** for this issue of the Thyrobuletin.

Ijenna Osakwe, Calgary Co-op



## KITCHENER-WATERLOO

On October 6, 2015, the Kitchener-Waterloo Area Chapter conducted an education meeting at the newly renovated Kitchener Public Library. Our speaker was Joan Lister, Healthcare and Communications Specialist, President and CEO of HealthComm Inc., Mississauga. Her topic was newly researched information titled, "Getting the Message Out: Sensitivity to Gluten and Thyroid Disease". Approximately 50 attended and eagerly asked questions regarding studies reported on this topic.

Joan Lister, HealthComm Inc.

We are very fortunate to be included as a part of the Health Education Program of the Kitchener Public Library. We thank them for all of their assistance. They provide us with the auditorium, amazing new equipment and an expert education team with lots of professional advertising for our meetings. We are also very fortunate to have the support of our local newspaper, The Record, who provides us with a grant of free advertising for our meetings.

We are also very blessed with a great, hard-working board. Without the help of each and every one of them, we would not have such a smooth-running, successful meeting. Thank you to all involved.



K-W Board Members (left to right): Kathy Pearce, Membership and Fundraising Chairman, Donna Kent and Derek De Ville, Education Chairmen, Joan De Ville, Program Chairman and Fatima Vitorino, Social Chairman.



## REGINA

On November 14, 2015, TFC had a display table at the Celiac Food Fair in Regina SK. There is a growing awareness of connections between various autoimmune disorders such as celiac disease and thyroid disease. Many people attending the Celiac Food Fair stopped by at the display table to check out the Health Guides, pick up a Thyrobuletin or a bookmark that directs them to our website for more information, or just to chat about their journey with thyroid disease. Some people had never heard of the Thyroid Foundation and were glad to know that we exist!

Donna Miniely (right) with Audrey Webb, president of the Regina chapter of the Celiac Association



# Our Goals

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

Thyroid Foundation of Canada Membership and Donation Form				La Fondation canadienne de la Thyroïde Formulaire d'adhésion et dons	
Name:		<input type="checkbox"/> New <input type="checkbox"/> Renew		<input type="checkbox"/> Gift for:	
Address:					
City:		Prov:	Postal Code:		
Tel.:		Email:			
MEMBERSHIP CATEGORY					
ONE YEAR				TWO YEAR	
Regular <input type="checkbox"/> \$25	Senior <input type="checkbox"/> \$20	Student <input type="checkbox"/> \$20	Family <input type="checkbox"/> \$30	Regular <input type="checkbox"/> \$40	Senior <input type="checkbox"/> \$30
				Student <input type="checkbox"/> \$30	Family <input type="checkbox"/> \$50
Members receive <i>Thyrobuletin</i> . Please indicate your preference:		<input type="checkbox"/> by regular mail		<input type="checkbox"/> to email above <input type="checkbox"/> no Thyrobuletin	
PAYMENT DETAILS					
Membership:		\$	<input type="checkbox"/> Cheque enclosed ( <i>payable to Thyroid Foundation of Canada</i> )		
<i>(All donations support the work of the Thyroid Foundation of Canada)</i> Donation:		\$	<input type="checkbox"/> Visa	<input type="checkbox"/> MasterCard	Exp. Date: <input type="text"/> <input type="text"/>
Total payment:		\$	Visa/MC #:		MM / YY
RECEIPT					
An official receipt for income tax purposes will be issued for all membership fees and donations (BN: 11926 4422 RR0001)					
Please indicate your receipt preference:		<input type="checkbox"/> by regular mail		<input type="checkbox"/> to email above	
Please send completed form to: <b>Thyroid Foundation of Canada, P.O. Box 298, Bath, ON K0H 1G0</b>					
Thank you for your support!			Happy Holidays to all!		

