



Clinical Thyroidology[®] for the Public

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EDITOR'S COMMENTS2

THYROID CANCER3

Surveillance for thyroid cancer in survivors of childhood and young adult cancer needs to be discussed between survivors and their healthcare providers

Children and young adults who are survivors of cancer have a higher risk to develop thyroid nodules and thyroid cancer since most treatments included radiation therapy. However, there is no consensus on surveillance for these survivors. Thus, the objective of this study was to develop guidelines for thyroid cancer surveillance in survivors of childhood, adolescent and young adult cancer.

Clement SC et al. 2018 Balancing the benefits and harms of thyroid cancer surveillance in survivors of childhood, adolescent and young adult cancer: recommendations from the International Late Effects of Childhood Cancer Guideline Harmonization Group in Collaboration with the PanCareSurFup Consortium. *Cancer Treat Rev* 63:28–39. PMID: 29202445.

HYPOTHYROIDISM5

Body weight appears to be the main levothyroxine dose adjustment variable

The dose of the Levothyroxine for any individual patient with hypothyroidism is different. However, many patients with hypothyroidism do not take the right dose and are either over-treated or undertreated. In this study, the authors evaluated the effect of sex, age and body weight on the blood level of thyroid hormone in patients taking Levothyroxine.

Younis IR et al 2018 Stable isotope pharmacokinetic studies provide insight into effects of age, sex, and weight on levothyroxine metabolism. *Thyroid* 28:41–49. Epub 2018 Jan 2. PMID: 29212434

HYPOTHYROIDISM7

Levothyroxine dosing in hypothyroidism

This study examined whether small changes in TSH blood test results affect quality of life, mood, and brain function in adults with hypothyroidism who were taking levothyroxine. Without knowing the type of change made, patients had their dose of levothyroxine either slightly increased, slightly decreased, or unchanged for six months. The patients completed questionnaires designed to assess quality of life, mood, and cognition before and at the end of the study period.

Samuels MH et al Effects of altering levothyroxine (L-T₄)

doses on quality of life, mood, and cognition in L-T₄ treated subjects. *J Clin Endocrinol Metab* (ePub ahead of print)

GRAVES' DISEASE.....8

Does having Graves' disease increase a patient's risk of suicide?

It has been noted that anxiety and other mood disorders are common in patients with hyperthyroidism and can be severe. One aspect of Graves' disease that may make underlying anxiety and mood disorders worse is the present of Graves' eye disease. This study was done to understand whether patients with Graves' disease, especially those with eye disease are at a higher risk of death from suicide.

Ferlov-Schwensen C et al Death by suicide in Graves' disease and Graves' orbitopathy: a nationwide Danish register study. *Thyroid*. October 30, 2017 [Epub ahead of print]. (<http://online.liebertpub.com/doi/pdf/10.1089/thy.2017.0365>)

THYROID CANCER.....10

Patients with advanced papillary thyroid cancer have fewer cancer recurrences after undergoing surgery by high-volume surgeons

It is known that patients under the care of high-volume thyroid surgeons have fewer surgical complications, such as recurrent laryngeal nerve injury and hypoparathyroidism, shorter hospital stay and lower costs related to the thyroid surgery. However, the impact of the surgeon's experience and number of patients on long-term outcomes after thyroid cancer surgery is not known. The aim of this study was to evaluate the impact of the surgeon volume on the recurrence rates in patients with advanced thyroid cancer and metastasis of the cancer to the lymph nodes of the neck.

Kim HI et al 2018 Surgeon volume and prognosis of patients with advanced papillary thyroid cancer and lateral nodal metastasis. *Br J Surg* 105:270–278. PMID: 29405275.

ATA ALLIANCE FOR THYROID PATIENT EDUCATION12

Friends of the ATA13

Support the ATA14

ATA Brochure: Thyroid Cancer15





www.thyroid.org

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Clinical Thyroidology for the Public

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EDITOR'S COMMENTS

Welcome to another issue of *Clinical Thyroidology for the Public*. In this journal, we will bring to you the most up-to-date, cutting edge thyroid research. We also provide even faster updates of late-breaking thyroid news through [Twitter](#) at [@thyroidfriends](#) and on [Facebook](#). Our goal is to provide patients with the tools to be the most informed thyroid patient in the waiting room. Also check out our friends in the **Alliance for Thyroid Patient Education**. The **Alliance** member groups consist of: the *American Thyroid Association*, *Bite Me Cancer*, *the Graves' Disease and Thyroid Foundation*, *the Light of Life Foundation*, *ThyCa: Thyroid Cancer Survivors' Association*, *Thyroid Cancer Canada*, *Thyroid Cancer Alliance* and *Thyroid Federation International*.

We invite all of you to join our **Friends of the ATA** community. It is for you that the American Thyroid Association (ATA) is dedicated to carrying out our mission of providing reliable thyroid information and resources, clinical practice guidelines for thyroid detection and treatments, resources for connecting you with other patients affected by thyroid conditions, and cutting edge thyroid research as we search for better diagnoses and treatment outcomes for thyroid disease and thyroid cancer. We thank all of the Friends of the ATA who support our mission and work throughout the year to support us. We invite you to help keep the ATA mission strong by choosing to make a donation that suits you – it takes just one moment to give online at: www.thyroid.org/donate and all donations are put to good work. The ATA is a 501(c)3 nonprofit organization and your gift is tax deductible.

May is **[Differentiated Thyroid Cancer Awareness Month](#)**.

In this issue, the studies ask the following questions:

- What is the best method of surveillance for thyroid cancer in survivors of childhood cancer?
- What role does body play in levothyroxine dosing?
- Do small changes in the dose of levothyroxine affect quality of life?
- Does Graves' disease increase a patient's risk of suicide?
- Does the amount of surgeries performed annually by a surgeon affect the rate of recurrence of thyroid cancer?

We welcome your feedback and suggestions. Let us know what you want to see in this publication. I hope you find these summaries interesting and informative.

— Alan P. Farwell, MD, FACE





THYROID CANCER

Surveillance for thyroid cancer in survivors of childhood and young adult cancer needs to be discussed between survivors and their healthcare providers

BACKGROUND

It is estimated that as of 2014 there were 419,000 survivors of childhood cancer in the United States. Further, children and young adults who are survivors of cancer have a higher risk to develop thyroid nodules and thyroid cancer since most treatments included radiation therapy. It is now clear that the once-held belief that high-dose radiation exposure destroyed thyroid tissue rather than causing cancer is incorrect. However, there is no consensus on surveillance for these survivors.

The main goal of the International Late Effects of Childhood Cancer Guideline Harmonization Group (IGHG) is “to establish a common vision and integrated strategy for the surveillance of chronic health problems and subsequent cancers in childhood, adolescent, and young adult cancer survivors”. Thus, the objective of this study was to develop guidelines for thyroid cancer surveillance in survivors of childhood, adolescent and young adult cancer.

THE FULL ARTICLE TITLE

Clement SC et al. 2018 Balancing the benefits and harms of thyroid cancer surveillance in survivors of childhood, adolescent and young adult cancer: recommendations from the International Late Effects of Childhood Cancer Guideline Harmonization Group in Collaboration with the PanCareSurFup Consortium. *Cancer Treat Rev* 63:28–39. PMID: 29202445.

SUMMARY OF THE STUDY

The IGHG in collaboration with the PanCareSurFup Consortium put together a panel of 33 international experts to formulate recommendations based on the available research. First, the existing recommendations were compared, and agreements and disagreements were determined. Then, after they discussed the possible benefits and harms of surveillance, the following questions were asked: who needs screening, what surveillance

method should be used, how frequently and for how long should thyroid cancer surveillance be performed and, what to do if abnormalities are identified. The PubMed database was the principal source to look for answers. Two members of the panel analyzed each paper. The level and strength of the recommendations, based on the available data, were graded according to well-established methods.

Childhood and young adult cancer survivors treated with radiotherapy or ¹³¹I-metaiodobenzylguanidine (MIBG), which accidentally exposes the thyroid gland, are at increased risk for the development of thyroid cancer. There is no data showing that chemotherapy alone is associated with a higher risk. As there is benefit of detecting thyroid cancer early, surveillance for thyroid cancer is reasonable for at-risk survivors. Childhood and young adult cancer survivors need to be counseled by their health care provider regarding their risk, as well as the advantages and disadvantages of surveillance. However, the authors were unable to provide recommendations regarding the preferred surveillance method to detect a thyroid nodule (neck palpation vs. thyroid ultrasound) and recommended that the decision be made by the individual healthcare provider after discussing with the patient. It was found reasonable to begin surveillance 5 years after exposure. The panel suggested that, if periodic thyroid palpation is chosen as the screening, it may be reasonable to repeat surveillance every 1 to 2 years, while, if thyroid ultrasonography is chosen as the screening method, to repeat surveillance every 3 to 5 years. Referral to a thyroid specialist is recommended if a thyroid nodule is found by either method of surveillance.

WHAT ARE THE IMPLICATIONS OF THIS STUDY?

Childhood and young adult cancer survivors at risk for thyroid cancer should be counseled about risk and benefits of surveillance and the available options for surveillance. However, there is no data to provide specific recom-





THYROID CANCER, continued

mentations. Initiation of surveillance and the surveillance method used needs to be chosen by the health care provider in consultation with the patient. This article highlights the importance of counseling and discussion,

summarizes available evidence and emphasizes the need for more research in this area.

— Liuska Pesce, MD

ATA THYROID BROCHURE LINKS

Thyroid Cancer (Papillary and Follicular): <https://www.thyroid.org/thyroid-cancer/>

Thyroid Cancer (Medullary): <https://www.thyroid.org/medullary-thyroid-cancer/>

Thyroid Nodules: <https://www.thyroid.org/thyroid-nodules/>

ABBREVIATIONS & DEFINITIONS

Cancer: a malignant growth or tumor caused by abnormal cells that divide without control.

Cancer surveillance: examinations and tests done at regular intervals to patients at risk for developing a certain type of cancer.

Thyroid cancer: Cancer arising from cells present in the thyroid gland, either the follicular thyroid cells (papillary thyroid carcinoma or follicular thyroid carcinoma) or the C-cells (medullary thyroid carcinoma).

Thyroid nodule: an abnormal growth of thyroid cells that forms a lump within the thyroid. While most thyroid nodules are non-cancerous (Benign), ~5% are cancerous.

Thyroid Ultrasound: a common imaging test used to evaluate the structure of the thyroid gland. Ultrasound

uses soundwaves to create a picture of the structure of the thyroid gland and accurately identify and characterize nodules within the thyroid. Ultrasound is also frequently used to guide the needle into a nodule during a thyroid nodule biopsy.

Radiotherapy: waves of radiation to treat cancers and tumors, as well as other conditions. As a general term, radiation means waves of energy, such as light or heat. The form of radiation used in cancer therapy is a high-energy type known as ionizing radiation

Ionizing radiation: radiation that can damage cells, causing cell death or mutation. It can originate from radioactive materials, x-ray tubes or specialized machines. It is invisible and not directly detectable by human senses





HYPOTHYROIDISM

Body weight appears to be the main levothyroxine dose adjustment variable

BACKGROUND

Hypothyroidism is a common medical condition which causes deficiency or low level of thyroid hormone. Patients with hypothyroidism are treated by taking thyroid hormone pills on a daily basis. The majority of patients with hypothyroidism take a synthetic form of thyroid hormone called Levothyroxine. Levothyroxine structure is identical to T₄, the main hormone secreted into the blood by the thyroid gland.

The dose of the Levothyroxine for any individual patient is different; the best dose should be able to keep the level of thyroid hormone tests (T₄ and TSH) within the normal range and help to improve the symptoms of hypothyroidism. However, many patients with hypothyroidism do not take the right dose and are either over-treated or undertreated. Over-treatment may cause irregular heart beats and bone loss in elderly and under-treatment may cause symptoms like weight gain, fatigue as well as other serious health issues like higher cholesterol level, and in severe cases heart problems and even death.

In this study, the authors evaluated the effect of sex, age and body weight on the blood level of thyroid hormone in patients taking Levothyroxine.

THE FULL ARTICLE TITLE

Younis IR et al 2018 Stable isotope pharmacokinetic studies provide insight into effects of age, sex, and weight on levothyroxine metabolism. *Thyroid* 28:41–49. Epub 2018 Jan 2. PMID: 29212434

SUMMARY OF THE STUDY

Participants in this study were patients with hypothyroidism who were treated at Georgetown University Medical Center. A total of 33 female and 8 male patients were included - 31 were younger and 10 were older than 60 years of age. They did not have any other major medical problem. Their weight ranged from 50 to 150 Kg. Their TSH and T₄ blood test results were normal on the dose of Levothyroxine they were taking. They each took a single dose of radioactive labeled Levothyroxine after 8 hours of fasting, followed by breakfast 2 hours later. The radioactive labeled thyroid hormone made it possible for the researchers to measure and follow the blood level of the dose taken by each study subject. Patients had blood tests before taking the dose and in regular intervals up to 312 hours after the dose. The results were compared between the participants based on their sex, age and weight.

The study showed that age and sex did not affect the concentration of radioactive labeled thyroid hormone in blood but the body weight of participants did. Thus, the dose of Levothyroxine that results in normal blood levels of T₄ and TSH is most closely related to the patient's body weight.

WHAT ARE THE IMPLICATIONS OF THIS STUDY?

The authors concluded that body weight should be considered when prescribing Levothyroxine and that the prescribed initial dose should be higher for patients with a heavier weight. The dose should be adjusted in regular intervals as necessary by blood test results and whenever there is a significant change in body weight.

— Shirin Haddady, MD

ATA THYROID BROCHURE LINKS

Hypothyroidism (Underactive): <https://www.thyroid.org/hypothyroidism/>

Older Patients and Thyroid Disease: <https://www.thyroid.org/thyroid-disease-older-patient/>

Thyroid Function Tests: <https://www.thyroid.org/thyroid-function-tests/>





HYPOTHYROIDISM, continued

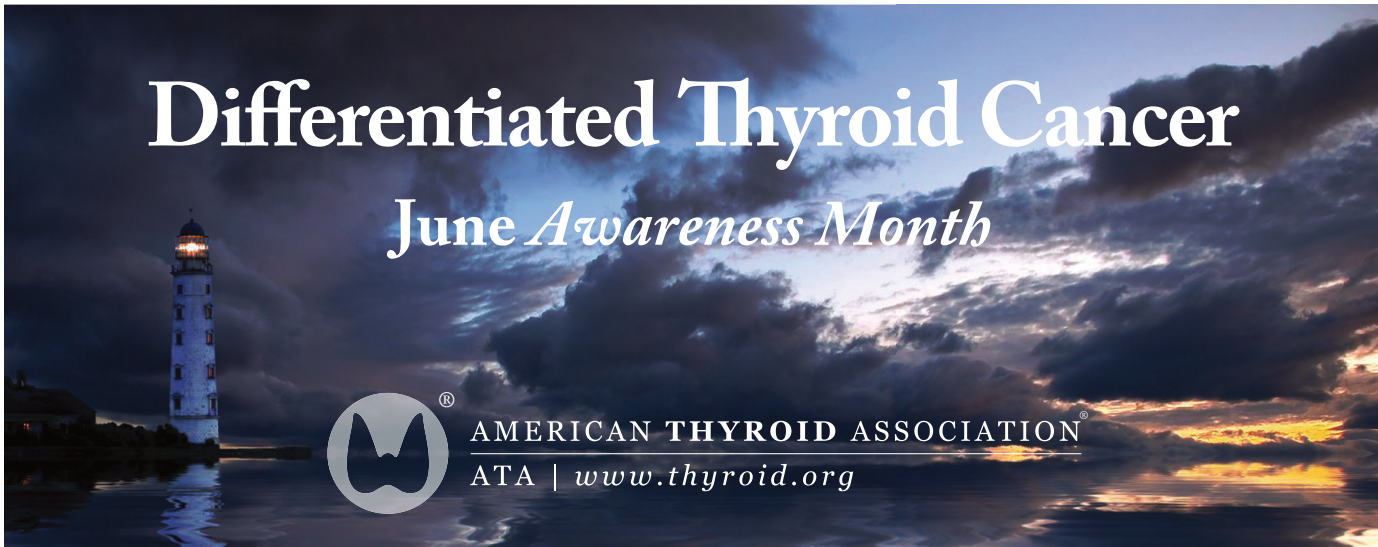
ABBREVIATIONS & DEFINITIONS

Hypothyroidism: a condition where the thyroid gland is underactive and doesn't produce enough thyroid hormone. Treatment requires taking thyroid hormone pills.

Levothyroxine (T4): the major hormone produced by the thyroid gland and available in pill form as Synthroid™, Levoxyl™, Tyrosint™ and generic preparations.

Thyroxine (T4): the major hormone produced by the thyroid gland. T₄ gets converted to the active hormone T₃ in various tissues in the body.

TSH: thyroid stimulating hormone — produced by the pituitary gland that regulates thyroid function; also the best screening test to determine if the thyroid is functioning normally.



Differentiated Thyroid Cancer
June Awareness Month

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HYPOTHYROIDISM

Levothyroxine dosing in hypothyroidism

BACKGROUND

It is well-known that thyroid hormone is required for normal brain function and many other aspects of health. In individuals with an underactive thyroid (hypothyroidism), thyroid hormone replacement, usually as levothyroxine, is needed to maintain normal thyroid hormone levels. Blood tests (TSH) are traditionally used to make sure that the dose of levothyroxine is correct.

However, it is unclear if small changes in TSH blood test results affect quality of life, mood, and cognition (brain function). This study was done in adults with hypothyroidism who were taking levothyroxine. Without knowing the type of change made, patients had their dose of levothyroxine either slightly increased, slightly decreased, or unchanged for six months. The patients completed questionnaires designed to assess quality of life, mood, and cognition before and at the end of the study period.

THE FULL ARTICLE TITLE

Samuels MH et al Effects of altering levothyroxine (L-T₄) doses on quality of life, mood, and cognition in L-T₄ treated subjects. J Clin Endocrinol Metab (ePub ahead of print)

SUMMARY OF THE STUDY

There were 138 patients who completed the study. The patients were 91% women, ranged in age from 27-70 years, and on average had taken levothyroxine use for 12 years. Regardless of the change in their levothyroxine dose, there were no substantial differences in scores related to quality of life, mood, and cognition. Although patients were not able to correctly guess whether their levothyroxine dose had been changed, they tended to prefer doses that they thought were higher.

WHAT ARE THE IMPLICATIONS OF THIS STUDY?

In patients with hypothyroidism, small changes in the dose of levothyroxine do not seem to affect quality of life, mood, or cognition (brain function). However, it remains unclear why some patients with hypothyroidism continue to have symptoms, even if their thyroid blood tests become normal after starting levothyroxine. Further research is needed to better understand this and potentially develop other treatment options.

— Angela M. Leung, MD, MSc

ATA THYROID BROCHURE LINKS

Hypothyroidism (Underactive): <https://www.thyroid.org/hypothyroidism/>

Thyroid Hormone Treatment: <https://www.thyroid.org/thyroid-hormone-treatment/>

ABBREVIATIONS & DEFINITIONS

Hypothyroidism: a condition where the thyroid gland is underactive and doesn't produce enough thyroid hormone. Treatment requires taking thyroid hormone pills.

Levothyroxine (T4): the major hormone produced by the thyroid gland and available in pill form as Synthroid™, Levoxyl™, Tyrosint™ and generic preparations.





GRAVES' DISEASE

Does having Graves' disease increase a patient's risk of suicide?

BACKGROUND

Graves' disease is the most common cause of hyperthyroidism in the United States. It has been noted that anxiety and other mood disorders are common in patients with hyperthyroidism and can be severe. Further, these symptoms may persist after the hyperthyroidism is controlled. One study found that even before patients had been diagnosed with hyperthyroidism, they were about 20% more likely to be taking psychiatric drugs or to have been hospitalized for psychiatric disorders, compared to individuals without thyroid disease. Once they were diagnosed with hyperthyroidism, their subsequent risk of receiving antipsychotic, antidepressant, or anxiolytic drugs or of being hospitalized for psychiatric disorders was even higher (about 50%).

One aspect of Graves' disease that may make underlying anxiety and mood disorders worse is the presence of Graves' eye disease. When present, symptoms of Graves' eye disease most often begin within 6 months of diagnosis of Graves' disease. While the majority of patients with eye disease is mild, occasionally it can be severe with double vision or disfiguring with protrusion of the eyes.

This study was done to understand whether patients with Graves' disease, especially those with eye disease are at a higher risk of death from suicide.

THE FULL ARTICLE TITLE

Ferlov-Schwensen C et al Death by suicide in Graves' disease and Graves' orbitopathy: a nationwide Danish

register study. *Thyroid*. October 30, 2017 [Epub ahead of print]. (<http://online.liebertpub.com/doi/pdf/10.1089/thy.2017.0365>)

SUMMARY OF THE STUDY

Patients above the age of 18 years with a new diagnosis of Graves' disease were studied. Patients with Graves' eye disease were included as were patients with psychiatric disorders. The data was compared to those who did not have Graves' disease. From mid-1995 through 2012, Graves' disease developed in 32,426 individuals in Denmark; 3965 of them also had Graves' eye disease.

The data showed that patients with Graves' disease were twice as common to die of unnatural causes, defined as accident, suicide, violence/homicide, and death of unknown manner, as compared to individuals without Graves' disease. The risk of death by suicide was three times higher in patients with Graves' eye disease.

WHAT ARE THE IMPLICATIONS OF THIS STUDY?

This is a valuable study that alerts us to be watchful for changes in the mood of a patient with Graves' disease—especially in a patient with disturbing eye signs or symptoms. A mental health assessment in patients with Graves' disease especially with the associated eye disease may be necessary for the patient's well-being and reduce risk of death from suicide /self harm.

—Vibhvasu Sharma, MD

ATA THYROID BROCHURE LINKS

Graves' Disease: <https://www.thyroid.org/graves-disease/>

Hyperthyroidism (Overactive): <https://www.thyroid.org/hyperthyroidism/>





GRAVES' DISEASE, continued

ABBREVIATIONS & DEFINITIONS

Graves' disease: the most common cause of hyperthyroidism in the United States. It is caused by antibodies that attack the thyroid and turn it on.

Graves' eye disease: also known as Graves ophthalmopathy or thyroid eye disease. This is most

often seen in patients with Graves' disease but also can be seen with Hashimoto's thyroiditis. Symptoms include inflammation of the eyes, eye muscles and the surrounding tissues as well as dry eyes, red eyes, bulging of the eyes and double vision.

Thyroid Awareness Monthly Campaigns

The ATA will be highlighting a distinct thyroid disorder each month and a portion of the sales for Bravelets™ will be donated to the ATA. The month of **June** is **Differentiated Thyroid Cancer Awareness Month** and a bracelet is available through the **ATA Marketplace** to support thyroid cancer awareness and education related to thyroid disease.





THYROID CANCER

Patients with advanced papillary thyroid cancer have fewer cancer recurrences after undergoing surgery by high-volume surgeons

BACKGROUND:

Surgery is an important initial step in the treatment of thyroid cancer. It is known that surgeons and hospitals with higher annual patient numbers for a specific surgery have a lower rate of complications and death related to surgery as compared to surgeons who perform a low number of operations. This has been reported for surgery performed for different cancers, including thyroid cancer. Patients under the care of high-volume thyroid surgeons have fewer surgical complications, such as recurrent laryngeal nerve injury and hypoparathyroidism, shorter hospital stay and lower costs related to the thyroid surgery.

However, the impact of the surgeon's experience and number of patients on long-term outcomes after thyroid cancer surgery is not known. Prior studies have showed that patients with advanced thyroid cancer who present with the spread of cancer to the lymph nodes of the neck (metastasis) at the time of diagnosis have a high risk of recurrence of the cancer after the initial treatment. The aim of this study was to evaluate the impact of the surgeon volume on the recurrence rates in patients with advanced thyroid cancer and metastasis of the cancer to the lymph nodes of the neck.

THE FULL ARTICLE TITLE:

Kim HI et al 2018 Surgeon volume and prognosis of patients with advanced papillary thyroid cancer and lateral nodal metastasis. *Br J Surg* 105:270–278. PMID: 29405275.

SUMMARY OF THE STUDY:

The study included 1103 patients with papillary thyroid cancer and lateral neck lymph node metastases who were treated in Seoul, South Korea between 1994 and 2011. All patients underwent total thyroidectomy with lateral neck lymph node dissection followed by radioactive iodine therapy. The patients were then followed with blood thyroglobulin tests measured every six months and yearly neck ultrasounds for an average of 81 months.

The 26 surgeons who performed the thyroid surgeries were divided in two groups, high-volume surgeons who performed at least 100 operations per year (average 395 operations per year) and low-volume surgeons who performed less than 100 operations per year (average 57 operations per year). Out of a total of 1103 patients, 796 underwent surgery by high-volume surgeons and 307 patients underwent surgery by low-volume surgeons.

A larger proportion of patients who had surgery by a high-volume surgeon had more advanced thyroid cancer with significant extension beyond the thyroid (33% vs. 25%), but also complete removal of the cancer during surgery (9% vs. 18%) as compared to patients who had surgery by a low-volume surgeon. The annual patient volume was a more important factor for thyroid cancer recurrence than the number of years in practice of a surgeon.

Patients undergoing surgery by a high-volume surgeon had a lower risk of local cancer recurrence as compared to those undergoing surgery by a low-volume surgeon. Among the 200 patients (18%) who had thyroid cancer recurrence in the neck area, 117 (15%) patients were in the high-volume group and 83 (27%) patients were in the low-volume group. The rate of metastases to other organs or deaths caused by thyroid cancer was not different between the two groups.

WHAT ARE THE IMPLICATIONS OF THIS STUDY?

The number of patients a thyroid surgeon operates on has an impact on the recurrence risk of the cancer in the neck area, however, not on cancer metastases to other organs or cancer-specific deaths in patients with advanced papillary thyroid cancer. A qualified high volume surgeon should perform the initial surgery for patients who present with advanced papillary thyroid cancer to decrease their high risk of recurrence during long-term follow-up.

— Alina Gavrila, MD, MMSC





THYROID CANCER, continued

ATA THYROID BROCHURE LINKS

Thyroid Cancer (Papillary and Follicular): <https://www.thyroid.org/thyroid-cancer/>

Thyroid Surgery: <https://www.thyroid.org/thyroid-surgery/>

ABBREVIATIONS & DEFINITIONS

Papillary thyroid cancer: the most common type of thyroid cancer. There are 4 variants of papillary thyroid cancer: classic, follicular, tall-cell and noninvasive follicular thyroid neoplasm with papillary-like nuclear features (NIFTP).

Cancer recurrence: this occurs when the cancer comes back after an initial treatment that was successful in destroying all detectable cancer at some point.

Recurrent laryngeal nerve: branch of the vagus nerve that supplies the muscles of the larynx, including the vocal cords. Injury of this nerve during thyroid surgery can result in hoarseness, loss of voice and breathing difficulty.

Hypoparathyroidism: low calcium levels due to decreased secretion of parathyroid hormone (PTH) from the parathyroid glands located next to the thyroid. This can occur as a result of damage to the glands during thyroid surgery and usually resolves.

Cancer metastasis: spread of the cancer from the initial organ where it developed to other organs, such as the lungs and bone.

Lymph node (LN): bean-shaped organ that plays a role in removing what the body considers harmful, such as infections and cancer cells.

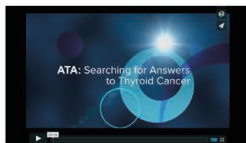
Lateral neck LN dissection: careful removal of all lymph nodes in the lateral compartment of the neck (lateral to the carotid arteries) in which cancer cells may have migrated.

Total thyroidectomy: surgery to remove the entire thyroid gland.

Radioactive iodine (RAI): this plays a valuable role in diagnosing and treating thyroid problems since it is taken up only by the thyroid gland. I-131 is the destructive form used to destroy thyroid tissue in the treatment of thyroid cancer and with an overactive thyroid.

Thyroglobulin: a protein made only by thyroid cells, both normal and cancerous. When all normal thyroid tissue is destroyed after radioactive iodine therapy in patients with thyroid cancer, thyroglobulin can be used as a thyroid cancer marker.

Watch how your donations help find answers to thyroid cancer



The American Thyroid Association (ATA) – Searching for Answers to Thyroid Cancer
April 17, 2016

♥ 13



Differentiated Thyroid Cancer – Support ATA's ongoing Research
April 17, 2016

♥ 19



Medullary Thyroid Cancer – Help the ATA Find a Cure
April 17, 2016

♥ 10



Anaplastic Thyroid Cancer – Support Research for Treatments
April 17, 2016

♥ 11

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ATA Alliance for Thyroid Patient Education

GOAL

The goal of our organizations is to provide accurate and reliable information for patients about the diagnosis, evaluation and treatment of thyroid diseases.

We look forward to future collaborations and continuing to work together toward the improvement of thyroid education and resources for patients.

WHO WE ARE (in alphabetical order)

AMERICAN THYROID ASSOCIATION

www.thyroid.org

ATA Patient Resources:

<http://www.thyroid.org/thyroid-information/>

Find a Thyroid Specialist: www.thyroid.org

(Toll-free): 1-800-THYROID

thyroid@thyroid.org

BITE ME CANCER

<http://www.bitemecancer.org>

info@bitemecancer.org

GRAVES' DISEASE AND THYROID FOUNDATION

www.gdatf.org

(Toll-free): 877-643-3123

info@ngdf.org

LIGHT OF LIFE FOUNDATION

www.checkyourneck.com

info@checkyourneck.com

THYCA: THYROID CANCER SURVIVORS' ASSOCIATION, INC.

www.thyca.org

(Toll-free): 877-588-7904

thyca@thyca.org

THYROID CANCER CANADA

www.thyroidcancer canada.org

416-487-8267

info@thyroidcancer canada.org

THYROID FEDERATION INTERNATIONAL

www.thyroid-fed.org

tfi@thyroid-fed.org



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Thyroid Cancer Canada
Cancer de la thyroïde Canada



ThyCa: Thyroid Cancer
Survivors' Association, Inc.™
www.thyca.org





AMERICAN
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FOUNDED 2005



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By subscribing to *Friends of the ATA Newsletter*, you will receive:

-  *Friends of the ATA e-news*, providing up-to-date information on thyroid issues, summaries of recently published articles from the medical literature that covers the broad spectrum of thyroid disorders., and invitations to upcoming patient events
-  Updates on the latest patient resources through the ATA website and elsewhere on the world wide web
-  Special e-mail alerts about thyroid topics of special interest to you and your family

We will use your email address to send you *Friends of the ATA e-news* and occasional email updates. We won't share your email address with anyone, and you can unsubscribe at any time.

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JOIN US

PLEASE JOIN OUR JOURNEY TO ADVANCED DISCOVERIES AND TREATMENT FOR THYROID DISEASE AND THYROID CANCER

As patients with thyroid disease navigate the challenges to their quality of life and researchers and physicians look for more effective directions, we at the ATA have our own destination—**funding for critical thyroid research, prevention, and treatment.** For 94 years, the ATA has led the way in thyroidology. It's a daily obstacle course to find new drugs, better treatments, advanced surgical methods, and more rapid diagnoses for the 20 million Americans who have some form of thyroid disease.



“The ATA was a valuable resource for our family when my dad was diagnosed with Anaplastic Thyroid Cancer. When you're faced with a detrimental diagnosis where even a few days can make the difference in life or death, understanding your options quickly is critical. The ATA website offers a one-stop shop for patients and caregivers to find specialists, current clinical trials, general thyroid cancer information, and links to other patient support groups and information.”

Mary Catherine Petermann

- Father who was diagnosed with Anaplastic Thyroid Cancer in 2006
- He was treated at Mayo Clinic
- He has clean scans as of October 2016

The ATA has paved the way with management guidelines for clinicians who diagnose and treat thyroid disease. For physicians treating pregnant women diagnosed with thyroid disease, our recent publication presents 97 evidence-based recommendations making sure that best practices are implemented with the latest, most effective treatment.



Through your generous support and donations, research takes the lead and hope is on the horizon. **Will you join us** in our campaign to raise **\$1.5 million** for thyroid research, prevention, and treatment? Your compassionate, tax-deductible gift will provide funds for:

- Research grants that pave the way for 1,700 ATA physicians and scientists who have devoted their careers to understanding the biology of and caring for patients affected by thyroid disease.
- Patient education for individuals and families looking for life-changing clinical trials, the best thyroid specialists, and cutting edge treatment and drugs.
- Professional education that offers a wealth of knowledge and leading-edge research for trainees and practitioners.
- A website that is the go-to resource for thyroid information for patients and practitioners alike. In 2016 alone, there were more than 3,700,000 website views of ATA's library of online thyroid information patient brochures.

Donations **of all sizes** will change the future for thyroid patients. You will make a direct impact on patients like Mary Catherine's father as he deals with Anaplastic Thyroid Cancer. You will help scientists like ATA Associate Member Julia Rodiger, Ph.D., a scientist at the National Institutes of Health, as she analyzes thyroid hormones for intestinal stem cell development.

Thyroid Cancer

(Papillary and Follicular)

WHAT IS THE THYROID GLAND?

The thyroid gland is a butterfly-shaped endocrine gland that is normally located in the lower front of the neck. The thyroid's job is to make thyroid hormones, which are secreted into the blood and then carried to every tissue in the body. Thyroid hormone helps the body use energy, stay warm and keep the brain, heart, muscles, and other organs working as they should.

CANCER OF THE THYROID

Thyroid cancer is relatively uncommon compared to other cancers. In the United States it is estimated that in 2016 approximately 64,000 new patients will be diagnosed with thyroid cancer, compared to over 240,000 patients with breast cancer and 135,000 patients with colon cancer. However, fewer than 2000 patients die of thyroid cancer each year. In 2013, the last year for which statistics are available, over 630,000 patients were living with thyroid cancer in the United States. Thyroid cancer is usually very treatable and is often cured with surgery (see [Thyroid Surgery brochure](#)) and, if indicated, radioactive iodine (see [Radioactive Iodine brochure](#)). Even when thyroid cancer is more advanced, effective treatment is available for the most common forms of thyroid cancer. Even though the diagnosis of cancer is terrifying, the prognosis for most patients with papillary and follicular thyroid cancer is usually excellent.

WHAT ARE THE TYPES OF THYROID CANCER?

Papillary thyroid cancer. Papillary thyroid cancer is the most common type, making up about 70% to 80% of all thyroid cancers. Papillary thyroid cancer can occur at any age. It tends to grow slowly and often spreads to lymph nodes in the neck. However, unlike many other cancers, papillary cancer has a generally excellent outlook, even if there is spread to the lymph nodes.

Follicular thyroid cancer. Follicular thyroid cancer makes up about 10% to 15% of all thyroid cancers in the United States. Follicular cancer can spread to lymph nodes in the neck, but this is much less common than with papillary cancer. Follicular cancer is also more likely than papillary cancer to spread to distant organs, particularly the lungs and bones.

Papillary and follicular thyroid cancers are also known as **Well-Differentiated Thyroid Cancers (DTC)**. The information in this brochure refers to the differentiated thyroid cancers. The other types of thyroid cancer listed below will be covered in other brochures

Medullary thyroid cancer. Medullary thyroid cancer (MTC), accounts for approximately 2% of all thyroid cancers. Approximately 25% of all MTC runs in families and is associated with other endocrine tumors (see [Medullary Thyroid Cancer brochure](#)). In family members of an affected person, a test for a genetic mutation in the RET proto-oncogene can lead to an early diagnosis of medullary thyroid cancer and, as a result, to curative surgery.

Anaplastic thyroid cancer. Anaplastic thyroid cancer is the most advanced and aggressive thyroid cancer and the least likely to respond to treatment. Anaplastic thyroid cancer is very rare and is found in less than 2% of patients with thyroid cancer. (See [Anaplastic thyroid cancer brochure](#).)

WHAT ARE THE SYMPTOMS OF THYROID CANCER?

Thyroid cancer often presents as a lump or nodule in the thyroid and usually does not cause any symptoms (see [Thyroid Nodule brochure](#)). Blood tests generally do not help to find thyroid cancer and thyroid blood tests such as TSH are usually normal, even when a cancer is present. Neck examination by your doctor is a common way in which thyroid nodules and thyroid cancer are found. Often, thyroid nodules are discovered incidentally on imaging tests like CT scans and neck ultrasound done for completely unrelated reasons. Occasionally, patients themselves find thyroid nodules by noticing a lump in their neck while looking in a mirror, buttoning their collar, or fastening a necklace. Rarely, thyroid cancers and nodules may cause symptoms. In these cases, patients may complain of pain in the neck, jaw, or ear. If a nodule is large enough to compress the windpipe or esophagus, it may cause difficulty with breathing, swallowing, or cause a "tickle in the throat". Even less commonly, hoarseness can be caused if a thyroid cancer invades the nerve that controls the vocal cords.



Thyroid Cancer

(Papillary and Follicular)

The important points to remember are that cancers arising in thyroid nodules generally do not cause symptoms, thyroid function tests are typically normal even when cancer is present, and the best way to find a thyroid nodule is to make sure that your doctor examines your neck as part of your periodic check-up.

WHAT CAUSES THYROID CANCER?

Thyroid cancer is more common in people who have a history of exposure to high doses of radiation, have a family history of thyroid cancer, and are older than 40 years of age. However, for most patients, we do not know the specific reason or reasons why thyroid cancer develops.

High dose radiation exposure, especially during childhood, increases the risk of developing thyroid cancer. Prior to the 1960s, X-ray treatments were often used for conditions such as acne, inflamed tonsils and adenoids, enlarged lymph nodes, or to treat enlargement of a gland in the chest called the thymus. All these treatments were later found to be associated with an increased risk of developing thyroid cancer later in life. Even X-ray therapy used to treat cancers such as Hodgkin's disease (cancer of the lymph nodes) or breast cancer has been associated with an increased risk for developing thyroid cancer if the treatment included exposure to the head, neck or chest. Routine X-ray exposure such as dental X-rays, chest X-rays and mammograms have not been shown to cause thyroid cancer.

Exposure to radioactivity released during nuclear disasters (1986 accident at the Chernobyl power plant in Russia or the 2011 nuclear disaster in Fukushima, Japan) has also been associated with an increased risk of developing thyroid cancer, particularly in exposed children, and thyroid cancers can be seen in exposed individuals as many as 40 years after exposure.

You can be protected from developing thyroid cancer in the event of a nuclear disaster by taking potassium iodide (see *Nuclear Radiation and the Thyroid brochure*). This prevents the absorption of radioactive iodine and has been shown to reduce the risk of thyroid cancer. The American Thyroid Association recommends that anyone living within 200 miles of a nuclear accident be given potassium iodide to take prophylactically in the event

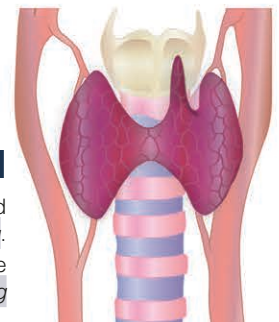
of a nuclear accident. If you live near a nuclear reactor and want more information about the role of potassium iodide, check the recommendations from your state at the following link: www.thyroid.org/web-links-for-important-documents-about-potassium-iodide/.

HOW IS THYROID CANCER DIAGNOSED?

A diagnosis of thyroid cancer can be suggested by the results of a fine needle aspiration biopsy of a thyroid nodule and can be definitively determined after a nodule is surgically excised (see *Thyroid Nodule brochure*). Although thyroid nodules are very common, less than 1 in 10 will be a thyroid cancer.

WHAT IS THE TREATMENT FOR THYROID CANCER?

Surgery. The primary therapy for all types of thyroid cancer is surgery (see *Thyroid Surgery brochure*). The extent of surgery for differentiated thyroid cancers (removing only the lobe involved with the cancer- called a lobectomy- or the entire thyroid – called a total thyroidectomy) will depend on the size of the tumor and on whether or not the tumor is confined to the thyroid. Sometimes findings either before surgery or at the time of surgery – such as spread of the tumor into surrounding areas or the presence of obviously involved lymph nodes – will indicate that a total thyroidectomy is a better option. Some patients will have thyroid cancer present in the lymph nodes of the neck (lymph node metastases). These lymph nodes can be removed at the time of the initial thyroid surgery or sometimes, as a later procedure if lymph node metastases become evident later on. For very small cancers (<1 cm) that are confined to the thyroid, involving only one lobe and without evidence of lymph node involvement a simple lobectomy (removal of only the involved lobe) is considered sufficient. Recent studies even suggest that small tumors – called micro papillary thyroid cancers – may be observed without surgery depending on their location in the thyroid. After surgery, most patients need to



FURTHER INFORMATION

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Thyroid Cancer

(Papillary and Follicular)

be on thyroid hormone for the rest of their life (see [Thyroid Hormone Treatment brochure](#)). Often, thyroid cancer is cured by surgery alone, especially if the cancer is small. If the cancer is larger, if it has spread to lymph nodes or if your doctor feels that you are at high risk for recurrent cancer, radioactive iodine may be used after the thyroid gland is removed.

Radioactive iodine therapy. (Also referred to as I-131 therapy). Thyroid cells and most differentiated thyroid cancers absorb and concentrate iodine. That is why radioactive iodine can be used to eliminate all remaining normal thyroid tissue and potentially destroy residual cancerous thyroid tissue after thyroidectomy (see [Radioactive Iodine brochure](#)). The procedure to eliminate residual thyroid tissue is called radioactive iodine ablation. This produces high concentrations of radioactive iodine in thyroid tissues, eventually causing the cells to die. Since most other tissues in the body do not efficiently absorb or concentrate iodine, radioactive iodine used during the ablation procedure usually has little or no effect on tissues outside of the thyroid. However, in some patients who receive larger doses of radioactive iodine for treatment of thyroid cancer metastases, radioactive iodine can affect the glands that produce saliva and result in dry mouth complications. If higher doses of radioactive iodine are necessary, there may also be a small risk of developing other cancers later in life. This risk is very small, and increases as the dose of radioactive iodine increases. The potential risks of treatment can be minimized by using the smallest dose possible. Balancing potential risks against the benefits of radioactive iodine therapy is an important discussion that you should have with your doctor if radioactive iodine therapy is recommended.

If your doctor recommends radioactive iodine therapy, your TSH will need to be elevated prior to the treatment. This can be done in one of two ways.

The first is by stopping thyroid hormone pills (levothyroxine) for 3-6 weeks. This causes high levels of TSH to be produced by your body naturally. This results in hypothyroidism, which may involve symptoms such as fatigue, cold intolerance and others, that can be significant. To minimize the symptoms of hypothyroidism

your doctor may prescribe T3 (Cytomel®, liothyronine) which is a short acting form of thyroid hormone that is usually taken after the levothyroxine is stopped until the final 2 weeks before the radioactive iodine treatment.

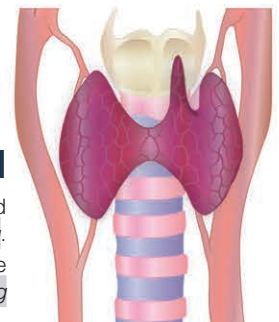
Alternatively, TSH can be increased sufficiently without stopping thyroid hormone medication by injecting TSH into your body. Recombinant human TSH (rhTSH, Thyrogen®) can be given as two injections in the days prior to radioactive iodine treatment. The benefit of this approach is that you can stay on thyroid hormone and avoid possible symptoms related to hypothyroidism.

Regardless of whether you go hypothyroid (stop thyroid hormone) or use recombinant TSH therapy, you may also be asked to go on a low iodine diet for 1 to 2 weeks prior to treatment (see [Low Iodine Diet FAQ](#)), which will result in improved absorption of radioactive iodine, maximizing the treatment effect.

TREATMENT OF ADVANCED THYROID CANCER.

Thyroid cancer that spreads (metastasizes) outside the neck area is rare, but can be a serious problem. Surgery and radioactive iodine remain the best way to treat such cancers as long as these treatments continue to work. However, for more advanced cancers, or when radioactive iodine therapy is no longer effective, other forms of treatment are needed. External beam radiation directs precisely focused X-rays to areas that need to be treated—often tumor that has recurred locally or spread to bones or other organs. This can kill or slow the growth of those tumors. Cancer that has spread more widely requires additional treatment.

New chemotherapy agents that have shown promise treating other advanced cancers are becoming more widely available for treatment of thyroid cancer. These drugs rarely cure advanced cancers that have spread widely throughout the body but they can slow down or partially reverse the growth of the cancer. These treatments are usually given by an oncologist (cancer specialist) and often require care at a regional or university medical center.



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Thyroid Cancer

(Papillary and Follicular)

WHAT IS THE FOLLOW-UP FOR PATIENTS WITH THYROID CANCER?

Periodic follow-up examinations are essential for all patients with thyroid cancer because the thyroid cancer can return—sometimes several years after successful initial treatment. These follow-up visits include a careful history and physical examination, with particular attention to the neck area. Neck ultrasound is an important tool to view the neck and look for nodules, lumps or cancerous lymph nodes that might indicate the cancer has returned. Blood tests are also important for thyroid cancer patients. Most patients who have had a thyroidectomy for cancer require thyroid hormone replacement with levothyroxine once the thyroid is removed (see [Thyroid Hormone Treatment brochure](#)). The dose of levothyroxine prescribed by your doctor will in part be determined by the initial extent of your thyroid cancer. More advanced cancers usually require higher doses of levothyroxine to suppress TSH (lower the TSH below the low end of the normal range). In cases of minimal or very low risk cancers, it's typically safe to keep TSH in the normal range. The TSH level is a good indicator of whether the levothyroxine dose is correctly adjusted and should be followed periodically by your doctor.

Another important blood test is measurement of thyroglobulin (Tg). Thyroglobulin is a protein produced by normal thyroid tissue and thyroid cancer cells, and is usually checked at least once a year. Following thyroidectomy and radioactive iodine ablation, thyroglobulin levels usually become very low or undetectable when all tumor cells are gone. Therefore, a rising thyroglobulin level should raise concern for possible cancer recurrence. Some patients will have thyroglobulin antibodies (TgAb) which can make it difficult to rely on the Tg result, as this may be inaccurate.

In addition to routine blood tests, your doctor may want to repeat a whole-body iodine scan to determine if any thyroid cells remain. Increasingly, these scans are only done for high risk patients and have been largely replaced by routine neck ultrasound and thyroglobulin measurements that are more accurate to detect cancer recurrence, especially when done together.

WHAT IS THE PROGNOSIS OF THYROID CANCER?

Overall, the prognosis of differentiated thyroid cancer is excellent, especially for patients younger than 45 years of age and those with small cancers. Patients with papillary thyroid cancer who have a primary tumor that is limited to the thyroid gland have an excellent outlook. Ten year survival for such patients is 100% and death from thyroid cancer anytime thereafter is extremely rare. For patients older than 45 years of age, or those with larger or more aggressive tumors, the prognosis remains very good, but the risk of cancer recurrence is higher. The prognosis may not be quite as good in patients whose cancer is more advanced and cannot be completely removed with surgery or destroyed with radioactive iodine treatment. Nonetheless, these patients often are able to live a long time and feel well, despite the fact that they continue to live with cancer. It is important to talk to your doctor about your individual profile of cancer and expected prognosis. It will be necessary to have lifelong monitoring, even after successful treatment.



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