THYROWORLD

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Working for the benefit of those affected by thyroid disorders throughout the world

Thyroid Federation International

Thyroid Patients Worldwide

In this Issue

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Message from the Editors

Welcome to the 2024 edition of TFI's annual newsletter and welcome to Athens. TFI is as always pleased to be able to be part of the Annual General Meeting of the European Thyroid Association – this year marks their 46th year. We have been present at these meetings since 1998. TFI celebrated its 25th anniversary in 2020 and will celebrate its 30th anniversary next year in June in Rio de Janeiro during the International Thyroid Congress, (ITC), co-sponsored by the American Thyroid Association (ATA), the European Thyroid Association (ETA), the Asia-Oceania Thyroid Association (AOTA), and the Latin American Thyroid Society (LATS).

TFI has grown from 6 founding members when the organization was created in Toronto back in 1995, to nearly 40 member organizations in all parts of the world! We encourage everyone who provides evidence-based information to thyroid patients to apply for membership. We are very glad to welcome patient-led and patient oriented organizations. In this magazine, you will find several articles from different sources. Sometimes these are readily published, sometimes they must be adapted to a patient level, and at times, the articles must be condensed to fit in the available space.

TFI is based on volunteer work and we pride ourselves on doing a great job these past years, with a very small team. We take part in conferences, sometimes just with a table and sometimes with lectures for the attendees. This year we are glad to say, many of TFI's Board members have participated in-person in nearly 20 conferences on all continents.

For the first time this year ThyroWorld is available in digital format on a USB card. Some printed copies will be available at our booth.

We would be delighted to meet you personally at our booth in the exhibition area. Feel free to contact us for more information: info@thyroid.org

THE EDITORS

Beate Bartès | Linda Henderson | Roko Granić | Katherine Keen

ThyroWorld

Deadline for the next issue: May 1, 2025
Send all submissions to:
The Editors, ThyroWorld
Thyroid Federation International
Email: tfi@thyroid-fed.org
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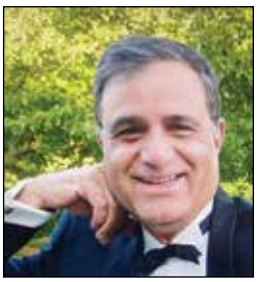
President's Message

ASHOK BHASEEN, M. PHARM, MMS,
PRESIDENT, THYROID FEDERATION
INTERNATIONAL



Ashok Bhaseen

Dear Readers,

It is with great pleasure that I extend my warmest greetings to all of you in this year's ThyroWorld. Whether you are an endocrinologist specializing in thyroid-related diseases or a patient navigating the complexities of such conditions, your presence and support are invaluable to us.

As the President of our non-profit organization that is made up of dedicated volunteers, I am continually inspired by the dedication and resilience demonstrated by both our medical professionals and patients alike. Together, we form a community driven by a shared commitment to advancing knowledge, improving treatments, and supporting one another through every step of the journey. I cannot thank enough for the support that we get from the medical community and their passion and dedication to our cause. Thanks to all our speakers and Medical Advisors that we can put together some quality Webinars and some insightful articles and patient tools to help our members across the globe.

Since the Pandemic we moved to remote connection, and continue to:

1. Leverage the online platforms for webinars and meetings, please visit our TFI YouTube channel for webinars on different Thyroid related topics
2. Continue our in person live AGM – this year in Athens, however we will maintain the online platform as well, since it is not feasible for everyone to travel yet
3. Remain financially responsible, stay nimble yet participate in the international forums and meetings
4. Keep moving ahead with our goals, plans and agenda for 2024-25 and beyond

TFI remains dedicated to addressing issues related to Thyroid patients and ensuring we are present on platforms and organizations that address these issues and find solutions.

Thanks to all our TFI members, Medical advisors, ITAW 2024 speakers, Board members, sponsors and supporters and those who follow us in helping us move ahead in 2024-25.

Throughout this ThyroWorld publication, you will find stories of courage, medical advancements, and personal triumphs. Each page reflects our collective efforts in promoting awareness, advocating for better care, and fostering a supportive environment for all those affected by thyroid-related diseases.

I invite you to immerse yourself in the articles, insights, and experiences shared within these pages. Let us celebrate our achievements, learn from our challenges, and reaffirm our commitment to making a meaningful difference in the lives of patients and families worldwide.

Thank you for your ongoing support and participation in our mission. Together, we are making strides towards a brighter, healthier future for everyone impacted by thyroid-related diseases.

Also, looking forward to seeing you all at the ITC 2025 at Rio de Janeiro, Brazil meeting. Best to all,

Ashok Bhaseen, President
Thyroid Federation International
ashok.bhaseen@thyroid-fed.org

TFI AGM and ETA congress 2023

Our 2023 AGM took place in Milan, Italy, on September 7- 8, once again as a "hybrid" event, with members from all around the world attending either on site or online. The members presented their organizations and their activities during the past year. We also had presentations from medical professionals and from pharmaceutical companies. The TFI board presented the yearly activity report, the financial report, the TFI projects and activities – various votes took place. The AGM was followed by the ETA congress in the beautiful historical location Ca' Granda of the university of Milan, where TFI had a booth in the exhibition area, attended many interesting lectures and met many old and new friends.
As every year, it was a great occasion to connect and to discuss with the members of TFI and medical professionals all over the world!

Conferences

European Society of Pediatric Endocrinology the Hague

With Johan de Graaf, Chair of the Dutch Hypofyse Foundation, Co-chair of the EPAG of the European Society of Endocrinology, Patient representative in ENDO-ERN, newly elected to board member of EURORDIS.

ESES Rome

With Dr. Julie Ann Sosa endocrine surgeon from University of California San Francisco (USA) specialized in thyroid cancer. She is leading the work group of the ATA for the Management of Thyroid Cancer.

Esicon Safes, Hyderabad

With Dr. Arun S. Menon, Associate Professor at the Department of Endocrinology, School of Medicine, Kochi, India and Secretary of the Indian Thyroid Society.

EndoBridge Antalya

With Robin Peeters, member of TFI Medical Advisory Board, internist-endocrinologist at Erasmus Medical Center in Rotterdam, the Netherlands, member of the board of the Dutch Internist Society and of the European Society for Endocrinology and Kristien Boelaert, Professor of Endocrinology at the University of Birmingham.

ESE Stockholm

Peter Lakwijk giving a presentation on “Thyroid diseases are NCDs” during the meeting of the European Society of Endocrinology, May 2024.

AOTA Conference, Indonesia

At AOTA Conference, Indonesia ITAW Patient Conference with President of Pita Tosca Ms. Astriani, May 2024.

Warsaw

Speaking on Interchangebility issues of Levothyroxin at AKADEMIA Endocrinology Polish Conference in Warsaw with Dr. Arturo Bossowiski, June 2024.

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Conferences *(continued from page 4)*

Reuters, Barcelona

Reuters Pharma at Barcelona, April 2024 —Claudia Roca, Catherine Coulouvrat, Ashok Bhaseen, Rebecca Lislee and Heidi Muller.

AOTA, Bali

Address at AOTA, Bali, May 2024, on Thyroid as NCDs.

Invitation to the 37th World Congress of Internal Medicine (WCIM) – October 2024

RICHARD ČEŠKA, CONGRESS PRESIDENT

Richard Češka

Prague, 30 October – 2 November, 2024

I would like to invite you to join the 37th World Congress of Internal Medicine (WCIM) which will be held in Prague, 30 October – 2 November, 2024.

The congress is organized by the International Society of Internal Medicine (ISIM). The purpose of ISIM is to promote scientific knowledge and unity in Internal Medicine, to further the education of young internists and to encourage friendship between physicians from all over the world.

The International Congresses of Internal Medicine are always outstanding events with a large attendance from the whole world.

The program will include a discussion on most internal medicine disciplines (cardiology, gastroenterology, diabetology, endocrinology, pneumology, oncology, rheumatology etc.) as well as the results of clinical trials.

We will focus not only on treatment, but also on diagnostic procedures and other aspects of internal medicine. A distinguished international faculty will deliver key lectures, while a large number of selected free communications will present data from multiple laboratories and clinical research centres from around the globe.

Let's meet together in Prague, the "capital of internal medicine", in October 2024!

We thank our Sponsors and Supporters

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Thank You!

Thank you to everybody who made this issue possible, most particularly Katherine Keen, who corrected the language of all non-native speakers among our authors, and Lynda Wegner who diligently took care of the layout.

Upcoming Events

To view the most up-to-date information, visit::
https://www.thyroid-fed.org/tfi-wp/events/

ETA, Sept. 7-10, 2024
Athens, Greee

WIA, Oct. 7-8, 2024
Milan, Italy

Pharma & Patient USA, Oct. 5-6, 2024
Boston, MA, USA

SAEMN, Oct. 7-11, 2024
Abidjan, Ivory Coast

Endobridge, October 17-20, 2024
Antalya, Turkey

WCIM, Oct. 30-Nov. 2, 2024
Prague, Czech Republic

ATA, Oct. 30-Nov. 3, 2024
Chicago IL, USA

ESPE – Nov. 16-18, 2024
Liverpool, UK

EDCC25, March 8-9, 2025
Bangkok, Thailand

ITC – June 18-22, 2025
Rio de Janeiro, Brazil

Annual Awareness Events

January
Thyroid Disease Awareness Month

May 25
World Thyroid Day

May 25 to 31
International Thyroid Awareness Week
www.thyroidweek.com

June 1
International Hypopara Awareness Day

July
Graves and TED Awareness Month

September
Thyroid Cancer Awareness Month

October 21
World Iodine Deficiency Day

Endocrine Disruptors

Threat to thyroid health and increasingly common in daily life

Katarina Fornander, author of several books on thyroid diseases and active blogger in Sweden.

Could the use of everyday items such as plastic bottles or lipstick be a contributor to your thyroid problems? Yes, because they often contain substances that interfere with hormonal health. Find out what endocrinologist Dr. Leonidas Duntas advises us to do about it.

Endocrine disruptors are a group of chemicals, with the capability of disturbing your hormones and therefore contributing to thyroid disease. They are present everywhere around us, including the air we breathe, the food we eat, what we put on our skin and the water we drink. Even in very low concentrations, their cumulative effect over many years add up to thyroid disease, learning disabilities, immune disturbances and much more.

Dr. Leonidas Duntas is Professor of Internal Medicine and Endocrinology at the University of Ulm, Germany, and Clinical and Research Associate at the Unit of Endocrinology, Diabetes and Metabolism, Evgenidion Hospital, University of Athens. He is also secretary of the European Thyroid Association (ETA). His concern for endocrine disruptors began when he realised the deep impact they have on the whole endocrine system.

- The endocrine systems' biology is complex and affected on various levels by these compounds. They are increasingly present in our daily lives. The thyroid is the most affected after our reproductive system. Endocrine disruptors are a huge problem, and it is difficult to make policies that prevent exposure to them.

Common and Everywhere

Among the many endocrine disruptors encountered in our daily life are pesticides in food, plasticides in food storage containers, flame retardants in furniture and per- and polyfluoroalkyl substances in our clothes. The list goes on. Plastic often contains the endocrine disruptor bisphenol A (BPA). But even when products are labeled "BPA-free", there is still reason to be concerned. New alternatives to BPA such as BPC, BPS and BPF are presented as non-toxic, but studies show they in fact are toxic, also to the thyroid.

- We know from animal studies that these substances can have effects on all levels of the endocrine system. They can disturb hormone production and break down; they can affect the concentration of thyroid hormones in organs and tissues and disturb the cellular action of hormones.

  The thyroid is affected in several ways:

- For example, the hypothalamic and T3 feedback loop is disturbed, we can have effects on synthesis of thyroid hormones and impaired entrance of iodine into the thyroid, while the transport of thyroid hormones may not function as well. Bisphenols and plastizers may act as antagonists to thyroid hormone receptor-binding and, in a dose-dependent manner, suppress the transcriptional activity stimulated by physiological concentrations of T3. Moreover, there is good evidence that BPA exerts a proinflammatory effect on the immune system, resulting in the initiation or aggravation of autoimmune thyroid disease.

Especially vulnerable groups are pregnant women, fetuses, and children:

- Endocrine disruptors affect maternal transfer of thyroid hormones. Thyroid hormones at normal levels are essential to growth and the developing brain of the fetus.

What you can do to lower impact?

If you get a bit uneasy hearing about this, you are not alone. Currently, it is not possible to entirely avoid endocrine disruptors. Dr Leonidas Duntas does give advice on how to lessen the burden:• Be aware and stay informed. This is very important. Try to decrease your exposure to these compounds. Find alternatives that are less toxic. Eating a diet rich in antioxidants may be helpful. Due to antioxidant actions in the body, we can presume that a diet rich in them may decrease our vulnerability and lower the effects of these compounds, even though this is yet to be confirmed by research.

Besides eating a diet rich in antioxidants, Dr Leonidas Duntas also suggests making sure it contains ample amounts of nutrients and keeping an eye on your fluid intake.

- Eat a diet that contains elements essential to good health, iodine, selenium, iron, zinc, vitamin B12 and vitamin D3, for example. They are important to build a strong immune system and have good thyroid health. Stay hydrated by drinking plenty of water and tea. Both tea and coffee are healthy beverages

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Endocrine Disruptors *(continued from page 7)*

as revealed in a very recent study (Levotto, Foods 2023).

More knowledge wanted

Currently there is no way to tell if your thyroid problems are caused by endocrine disruptors.

- I see patients every day with, for example, Hashimoto's disease, but I cannot say if they got it due to endocrine disruptors. Endocrine disruptors have long-term effects – you are not exposed for one month and then you have a thyroid problem. These compounds are present at very low concentrations and have effects over a long time. By the time a patient clinically presents with thyroid disease, cancer and fertility problems, they have been exposed for many years. Of course, there are genetics and environmental factors that playing together may induce thyroid disease.

Few human studies have been done, but the animal studies are telling us loud and clear that these compounds have detrimental effects on our endocrine system.

Reducing the endocrine disruptors in our environment

In July 2007, the European Commission (EC) brought the regulation REACH into force. REACH stands for Registration, Evaluation, Authorisation and Restriction of Chemicals. It was created to protect human health and the environment. This regulation is overdue for a revision, which should have been carried out in 2022.

The European Society of Endocrinology (ESE), together with its members and partners at the European level, the European Council of Affiliated Societies (ECAS), the European Society for Paediatric Endocrinology (ESPE) and the European Thyroid Association (ETA), and joined by 41 European National Societies, recently submitted a petition to urge the EC to publish the REACH revision without any further delay. Specifically, the petition calls for an ambitious REACH revision to be published no later than June 2023. We have been invited to Brussels at the beginning of June to discuss it with the EC. Hopefully we can achieve a positive change for millions of Europeans.

Besides influencing the European Commission, Dr. Leonidas Duntas underlines that it is also important to put pressure on your local authorities and public stakeholders to restrict the use of these compounds.

- Otherwise they will increase in our environment and their impact on health and economy is already very widespread.

FACT BOX: What are endocrine disruptors?

The problem of endocrine disruptors is well known by leading health organisations, and the World Health Organisation (WHO) gives the following definition of what endocrine disruptors are:

"An endocrine disruptor is an exogenous substance or mixture that alters function(s) of the endocrine system and consequently causes adverse health effects in an intact organism, or its progeny, or (sub) populations."

FACT BOX: Where can endocrine disruptors be found?

Endocrine disruptors are common in your environment. Here are a few everyday items to be careful about:

- Plastic bottles and containers (including baby food bottles)
- Liners of metal food cans
- Detergents
- Flame retardants
- Food
- Toys
- Clothes
- Cosmetics
- Pesticides
- Carpets

References:

https://www.niehs.nih.gov/health/topics/agents/endocrine/index.cfm

Ashok Bhaseen, Canada, Dr. Leonidas Duntas, Greece, Yvonne Andersson, Sweden and Bente Julie Lasserre, Denmark.

Hypothyroidism and Type D Personality

The Journal of Clinical Endocrinology & Metabolism, dgae140, https://doi.org/10.1210/clinem/dgae140

This study is published in the Journal of Clinical Endocrinology and Metabolism and it explores the connection between hypothyroidism and Type D personality.

Summary

A team of researchers (including representatives of Thyroid Federation International) conducted an international online survey called E-MPATHY (E-Mode Patient self-Assessment of THYroid therapy). Participants from various countries filled out questionnaires about their health, including questions related to thyroid function and personality traits.

Hypothyroidism is a condition where the thyroid gland doesn't produce enough thyroid hormones. Thyroid hormones are crucial for regulating metabolism, energy, and overall bodily functions. A significant minority of the people with hypothyroidism experience persistent symptoms like fatigue, weight gain, and depression despite treatment with thyroid hormones.

Type D personality, also known as "distressed" personality, is characterized by high levels of negative emotions and social inhibition. People with this personality type tend to feel unhappy, anxious, and avoid social interactions, which can lead to stress and mental health issues.

The study aimed to explore how type D personality related to patient characteristics and to patient outcomes like dissatisfaction and impact of hypothyroidism on daily life.

Researchers wanted to understand whether people with hypothyroidism are more likely to have a Type D personality compared to the general population.

Key Findings

1. **Increased Type D Personality in Hypothyroid Patients:**

   The survey revealed that individuals with hypothyroidism are more likely to exhibit Type D personality traits. The prevalence of the Type D personality was 54%, approximately twice as high as that in the general population.

2. **Impact on Mental Health:**

   Hypothyroid patients with Type D personality reported higher levels of depression, anxiety, and overall psychological distress. This suggests that having both conditions can significantly affect a person's mental health and quality of life.

   Type D personality was associated with perceptions of poor control of the symptoms of hypothyroidism by medication, dissatisfaction with care and treatment of hypothyroidism, and a negative impact of hypothyroidism on everyday living.

3. **Social and Emotional Challenges:**

   People with hypothyroidism and Type D personality tend to experience more social and emotional difficulties. They are more likely to feel isolated and avoid social situations, which can worsen their mental health.

4. **Need for Integrated Care:**

   The findings highlight the importance of addressing both the physical and psychological aspects of hypothyroidism.

(continued on page 10)

Hypothyroidism and Type D Personality *(continued from page 9)*

Implications

Understanding the link between hypothyroidism and Type D personality can help in developing more effective treatment plans. By recognizing the psychological challenges faced by hypothyroid patients, doctors can offer more holistic care that addresses both physical and mental health needs.

Conclusion

The study underscores the importance of recognizing and treating the psychological aspects of chronic physical conditions like hypothyroidism.

In summary, if you have hypothyroidism, it's not just about managing physical symptoms. It's also crucial to pay attention to your mental health, as there may be a higher likelihood of experiencing negative emotions and social inhibition associated with Type D personality. Seeking comprehensive medical care that includes mental health support can make a significant difference in your quality of life.

The study highlights that doctors managing people with hypothyroidism need more awareness of the emotional needs of patients.

The full text of the study is available on https://doi.org/10.1210/clinem/dgae140

Summary by Peter Lakwijk (member of the E-MPATHY team).

News from the Thyroid Field

Thyroid and Young Adults

VESA ILVESMÄKI, SPECIALIST IN ENDOCRINOLOGY AND INTERNAL MEDICINE, MD, WITH SPECIAL EXPERTISE IN DIABETES CARE

Earlier published in "Kilpi", the magazine for members of Kilpirauhasliito Finland.

Many chronic diseases become more common with age, but this is not true for thyroid diseases. Thyroid diseases can occur at any age, including in young adults. This article discusses thyroid diseases in young adults.

Underactive Thyroid (Hypothyroidism)

Hypothyroidism, or underactive thyroid, is the most common thyroid disease. In Finland, 5-6% of the population has hypothyroidism, which means more than 340,000 people. Symptoms of hypothyroidism are vague, but the main symptom is extreme fatigue that doesn't improve with rest or sleep. Other symptoms include swelling, weight gain, feeling cold, constipation, dry skin, and hair loss. Often, these symptoms are mistaken for mental health issues like depression.

Blood tests (FT4, TSH) can clarify the diagnosis. If the patient's symptoms are unclear, the diagnosis can be delayed for years, causing significant harm and affecting study or work performance. Untreated hypothyroidism reduces fertility, possibly leading to infertility, and worsens quality of life. It also increases the risk of diabetes and heart diseases due to weight gain.

The most common cause of hypothyroidism is an autoimmune inflammation of the thyroid (autoimmune thyroiditis). This is diagnosed with a blood test showing high levels of TPOAb antibodies. Hypothyroidism is usually permanent and requires lifelong thyroid hormone (levothyroxine) treatment. Even with treatment, 10-

20% of patients may still have symptoms similar to hypothyroidism. This could be because their bodies don't convert T4 to T3 properly, causing a T3 deficiency at the cellular level. This can be treated by adding T3 medication alongside T4. Unfortunately, many patients who need T3 treatment don't get diagnosed or treated correctly, often being misdiagnosed with depression. However, it's important to note that chronic fatigue can have many other causes besides hypothyroidism and diagnosing it can be challenging.

Overactive Thyroid (Hyperthyroidism)

The most common cause of hyperthyroidism, or overactive thyroid, is Graves' disease (70% of cases). This disease peaks in people aged 30-40 and is almost 10 times more common in women than in men. In young people, hyperthyroidism symptoms are usually severe, including heart palpitations, increased sweating, tremors, frequent

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Thyroid and Young Adults *(continued from page 10)*

bowel movements, weight loss, insomnia, difficulty concentrating, and nervousness. Symptoms usually develop over a few weeks or months and are often severe enough for the patient to seek medical help promptly.

Graves' disease is also an autoimmune disease, diagnosed with a blood test showing high levels of anti-TSHRAb antibodies. This test is usually done when the disease is first diagnosed and may be checked again later if needed. Besides Graves' disease, hyperthyroidism can be caused by toxic nodular goiter or toxic adenoma, but these are less common. Treatment for hyperthyroidism starts with carbimazole, regardless of the cause. Beta-blockers (propranolol or metoprolol) may be needed early on to relieve symptoms. The initial diagnosis and treatment are handled by a primary care doctor, who then refers the patient to a specialist for further management.

Thyroid Inflammations

The thyroid can be affected by various inflammations (thyroiditis), with the most common being autoimmune thyroiditis and subacute thyroiditis. These are fairly common, especially in younger adults. Postpartum thyroiditis can also occur but is not covered here. Infections caused by bacteria and other microbes are rare. Autoimmune thyroiditis usually leads to hypothyroidism with high TPOAb antibody levels, and this hypothyroidism is usually permanent.

Subacute thyroiditis often causes severe pain and tenderness in the thyroid. The disease progresses quickly, usually within a few days. Initially, there may be symptoms of hyperthyroidism due to damaged thyroid tissue releasing hormones into the bloodstream. However, the actual hormone production hasn't increased, so carbimazole isn't used. Diagnosis is clinical, meaning the doctor must recognize the disease to diagnose it correctly. Blood tests for inflammation markers (ESR and CRP) are usually very high. Treatment includes a course of corticosteroids (e.g., prednisolone) for at least a month. Beta-blockers can relieve hyperthyroid symptoms, and pain can be managed with painkillers (e.g., paracetamol). After the hyperthyroid phase, there is usually a period of hypothyroidism, which is treated with levothyroxine. This phase is generally temporary, lasting 6-12 months, but sometimes the thyroiditis becomes chronic, requiring thyroid surgery.

Thyroid Nodules and Tumors

Thyroid nodules are common, occurring in about 50% of people. Most nodules are harmless and don't need treatment or monitoring. Thyroid nodules are also common in young people. Ultrasound can easily examine these nodules. The radiologist can determine from the ultrasound image if the nodule is suspicious and if a biopsy or follow-up is needed. About 5% of nodules larger than 1 cm are cancerous. Benign nodules can be cysts or adenomas.

Thyroid cancer often appears as a lump in the neck. Sometimes it's found accidentally during thyroid surgery for another reason, like goiter. There are four types of thyroid cancer, with papillary and follicular being the most common. The incidence of these cancers is steadily increasing worldwide, including in Finland, for unknown reasons.

Thyroid cancer is four times more common in women than in men. It's rare in children. The incidence starts to rise in women from age 20 and peaks between 40-64 years. Among women, thyroid cancer is the eighth most common cancer in the 20-69 age group. In 2021, 371 women and 127 men were diagnosed with thyroid cancer in Finland. Treatment outcomes are excellent, and most patients recover fully. The five-year survival rate is 94% for women and 85% for men. Currently, almost 11,000 Finns have recovered from thyroid cancer.

Summary

Young adults can develop various thyroid diseases. It's important for doctors to examine the thyroid during check-ups. If the thyroid feels abnormal, an ultrasound is recommended. If symptoms suggest thyroid dysfunction, blood tests (TSH, FT4) should be done. It's best to avoid unnecessary lab tests in symptom-free individuals. Most thyroid diseases and the symptoms can be treated effectively, giving most patients a nearly unchanged quality of life.

Now available on our Youtube Channel

Youtube channel

https://www.youtube.com/@ThyroidFederationInternational

Webinar NCDs, 25 May 2024
https://www.youtube.com/watch?v=nktYGHCAuJo

Webinar Cardiovascular risks, May 31, 2024
https://www.youtube.com/watch?v=c5f8DU7Mx5A

Miscarriage can Mean More than You Think

Sofie Bliddal, MD, PhD, project coordinator at COPL at Hvidovre Hospital, Denmark.

Earlier published in "Stof", the magazine for members of Stofskifteforeningen Denmark.

For couples who experience a miscarriage, it is often a dream of a life with a child that is lost. Women with thyroid disease have a higher risk of miscarriage, but the loss itself can also be the first symptom of a disease that develops later. Therefore, it is important to research the mechanisms behind miscarriage to understand the consequences of the loss – both for future pregnancies and for the woman herself.

One in four pregnancies end in a miscarriage. Some very early, where there are just two lines on a positive pregnancy test. Others later in the pregnancy, where heart activity has been seen on an ultrasound scan, or maybe even a lively foetus at the nuchal translucency scan around week 12.

Very common, but still taboo

The risk of miscarriage decreases as the pregnancy progresses. Although exact numbers are not available, it is estimated that about 90 percent of all miscarriages occur before gestational week nine. Despite how common it is to experience a miscarriage, it is still very taboo, and many couples wait to share the joyful news with family and friends until they have had a nuchal translucency scan around week 12. When a miscarriage occurs, many couples are therefore still surprised that it could happen to them, but also supprised to learn how many in their circle of friends, colleagues, and family who have experienced the same. It is completely okay to be private about ones' own grief, but many find it helpful to talk through their sorrow and the process. Part of the research into miscarriages is therefore also to demystify and destigmatize by sharing our knowledge.

Why do miscarriages happen?

Originally, we interpreted miscarriages as "nature's way." "There was probably something wrong with the foetus" – and in a way, it was "for the best." "Go home and try again".

We now know that it is only in about half of all lost foetuses that an abnormal number of chromosomes can be found. For them, we can say that this must be the explanation for the loss.

But for the other half, we lack a good explanation of what happened. Many things can be imagined; small lethal changes (mutations) in genes, altered cell division in the early stages, infections, blood clots in the placenta, errors in the sperm cells' DNA, endocrine

disruptors, lifestyle factors such as smoking, alcohol, and BMI – and thyroid disease and autoimmunity in the woman. Although many of these factors have been shown to be associated with the risk of miscarriage, it is rarely investigated whether the foetus had chromosomal abnormalities that could explain the loss. For example, both the proportion of chromosomal abnormalities in the foetus and the proportion of thyroid disease and autoimmunity increase with the age of the woman (and the man).

Without examining the foetus, we therefore do not know whether the association with miscarriage is due to age-related chromosomal abnormalities or not. If the loss is not due to chromosomal abnormalities, there may be an opportunity to learn from that loss; where should we focus if we want to try to prevent miscarriages in the future?

Thyroid disease and miscarriages

We know that there is an increased risk of miscarriage in women with thyroid disease. The risk decreases with treatment of high or low thyroid function. However, we do not have a good treatment for women with thyroid autoimmunity who have a normal thyroid function. Our current understanding is that the association between thyroid autoimmunity and miscarriage is due to a generally overactive immune system, which leads to attacks on both the thyroid and a rejection of the foetus. Therefore, the solution for some women may be to treat the immune system with immunosuppressive medication. Before this can become relevant, we need to be better at distinguishing who could benefit from such treatment, as we know that many Danish women have autoimmunity against the thyroid, and not all experience miscarriages.

(continued on page 13)

Miscarriage *(continued from page 12)*

A key to understanding thyroid disease?

By better examining miscarriages, we can probably also learn more about thyroid disease. From Danish registers and foreign studies, researchers have now shown that women who experience miscarriages early in life have an increased risk of a wide range of diseases later in life, such as cardiovascular disease and autoimmune thyroid disease. A miscarriage can therefore be the first sign for some that there is disease on the way. By examining miscarriages, we as researchers hope that we will not only find women with undiagnosed thyroid disease but also that we can become better at predicting who will develop disease later on. And not least, clarify the mechanisms behind the associations that we can otherwise only describe but do not fully understand.

Copenhagen Miscarriage Study

At Hvidovre Hospital in Denmark, the "Copenhagen Miscarriage Study," commonly known as COPL, has been running for almost three years under the leadership of Professor Henriette Svarre Nielsen. The project is very ambitious in its sample collection with the overarching goal of understanding all aspects of miscarriage. Both the woman and her male partner (if possible) are examined with a multitude of tests to shed light on the importance of genetics, lifestyle, ethnicity, bacterial flora in the vagina and intestines, uterine malformations, weight, blood pressure, and so on. To our great excitement, the Novo Nordisk Foundation has awarded the project 25 million Danish kroner (approx. 3.3 million euros) to continue with a special focus on the thyroid and polycystic ovary syndrome (a hormonal disorder that, among other things, causes irregular menstruation).

Applicants included Professor Steen Bonnema and Chief Physician Dorte Glintborg from Odense University Hospital in Denmark. Since December 2023, another project site has therefore also been opened in Odense. The project will henceforth be called the "Copenhagen Odense Miscarriage Study," commonly known as COPL2.

At the time of writing, the Novo Nordisk Foundation has additionally granted 10 million Danish kroner (approx. 1.3 million euros) to offer participants in the project the opportunity to be followed with scans and blood tests in their next pregnancy. The grant is given with a focus on the development of the thyroid from the time of miscarriage, after the miscarriage, and during the next pregnancy.

Miscarriage

In Denmark, investigation is offered to couples who experience recurrent miscarriage, defined as three consecutive miscarriages or two late miscarriages (after seeing life at the nuchal translucency scan).

Women who have experienced a miscarriage can, according to national guidelines, have their thyroid function measured by their general practitioner the next time they become pregnant.

Information about the COPL project can be found at www.graviditetstab.dk and Instagram COPL_project.

Sofie Bliddal received the Harrington De Visscher Prize at the international thyroid conference ETA in Milan in September 2023. She received the award for her research on the thyroid in pregnant women.

Quote:

From Danish registers and international cohort studies, researchers have now shown that women who experience a miscarriage early in life have an increased risk of a wide range of diseases later in life, such as cardiovascular disease and autoimmune thyroid disease.

By examining miscarriages, we as researchers hope that we will not only find women with undiagnosed thyroid disease, but also that we can better predict who will develop disease later in life.

Sofie Bliddal received the Harrington De Visscher Prize at the international thyroid conference ETA in Milan in September 2023. She received the award for her research on the thyroid in pregnant women.

American Thyroid Association and European Thyroid Association Release Consensus Statement on Thyroid Eye Disease

Kimberly Dorris, Executive Director, Graves' Disease & Thyroid Foundation

In December 2022, the American Thyroid Association (ATA) and the European Thyroid Association (ETA) released a jointly crafted statement on the management of thyroid eye disease (TED).[1] The consensus statement (CS) was produced as a resource for endocrinologists to help ensure that autoimmune thyroid patients who are showing signs of thyroid eye disease receive a timely diagnosis and referral to specialist care. The GDATF was honored to be one of two patient organizations (along with the Thyroid Organization of the Netherlands) invited to review a draft of the statement and to provide feedback.

Although patients who are euthyroid or hypothyroid can develop TED, the majority of TED patients have been diagnosed with hyperthyroidism due to Graves' disease. The CS notes that approximately 6% of Graves' patients have moderate-to-severe TED and 0.5% of patients have sight threatening TED.

While parts of the consensus statement are highly technical, including an explanation of the different treatment options for varying levels of severity (including how they work, estimated cost, effectiveness, and safety), the CS also includes practical advice for patients. The following suggestions will help ensure patients receive the best care possible (and hopefully prevent new onset or worsening TED):

- Ask for measurement of TSH receptor antibodies (TRab)
- Ask for a list of signs and symptoms to watch out for (such as, dry eye, pain, grittiness, light sensitivity, swelling, bulging, and eyelid retraction)
- Stop smoking (ask your doctor for smoking cessation resources if needed)
- Keep up with doctor's appointments and take medications as directed in order to normalize thyroid levels.
- For patients with moderate-to-severe or sight-threatening TED, ask your doctor about treatment options for hyperthyroidism other than radioactive iodine – or consider a course of steroid therapy in conjunction with RAI if that is the recommended treatment option.
- Avoid hypothyroidism after RAI (ask your doctor for a new set of labs if you start experiencing symptoms such as fatigue, weight gain, cold intolerance, dry skin, constipation, and heavier periods)
- Consider a 6-month course of selenium supplementation for mild TED (but pay attention to your doctor's dosing recommendations, as excess consumption can lead to side effects)
- Ask for a referral for specialist care if needed to ensure a correct diagnosis, as TED symptoms can sometimes overlap with those of other orbital conditions.

The CS also explains a number of "local and lifestyle" measures that can provide symptom relief, noting that "watchful monitoring will be sufficient in the majority of patients with mild disease, which in due course will remit completely or partially."

- Manage dry eye with artificial tears
- If needed for nighttime, use an eye mask, tape lids shut, or use a headband over a Vaseline-moistured eye pad
- Elevate the head of the bed
- Use dark glasses for light sensitivity
- Use "selective ocular occlusion" (for example, eye patches) or Fresnel prisms for double vision

The CS concludes by highlighting gaps in our knowledge where more research is needed in order to fully understand TED, for example:

- Is there an easy screening tool that patients can use to self-diagnose TED early?

(continued on page 15)

[1] Management of Thyroid Eye Disease: A Consensus Statement by the American Thyroid Association and the European Thyroid Association. Task Force Members: Henry B. Burch, Petros Perros, Tomasz Bednarczuk, David S. Cooper, Peter J. Dolman, Angela M. Leung, Ilse Mombaerts, Mario Salvi, and Marius N. Stan. Thyroid® 2022 32:12, 1439-1470.

Consensus Statement on Thyroid Eye Disease *(continued from page 14)*

- Are there reliable biomarkers to predict the development of TED in newly diagnosed Graves' patients?
- Is race a risk factor for TED?
- Is selenium useful in selenium sufficient areas?
- How do the different medical options compare head-to-head in terms of cost and effectiveness?
- What are the underlying mechanisms to RAI that increase the risk of TED?

To view the guidance in full, please visit the American Thyroid Association's web page:

https://www.thyroid.org/management-of-thyroid-eye-disease/

For a downloadable PDF, visit the journal Thyroid at:

https://www.liebertpub.com/doi/pdf/10.1089/thy.2022.0251

News from the Thyroid Field

Thyroid Eye Disease and Quality of Life

Results of GDATF Survey Published in Frontiers in Endocrinology

Results from a patient survey commissioned by the Graves' Disease & Thyroid Foundation were published in November 2023 in Frontiers in Endocrinology. "How Patients Experience Thyroid Eye Disease" offers patients, physicians, and caregivers a comprehensive look at quality-of-life issues for those living with TED. (1)

The survey included 62 questions and a free-form response section designed to provide insight on time to diagnosis, symptoms experienced, impact on work and other daily activities, impact on relationships and mental health, perceived effectiveness of different treatment options, and difficulty getting health insurers to pay for treatment.

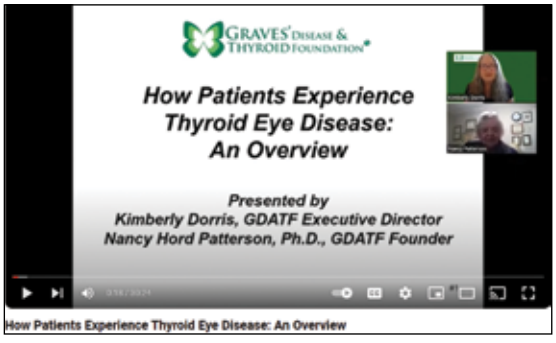
The authors – including GDATF Chief Medical & Scientific Officer Dr. Terry Smith and Executive Director Kimberly Dorris – concluded, "The findings reported here reveal a perception among patients that some physicians lack an awareness of TED and fail to recognize the signs, symptoms, and negative impact of this disease on QoL. These shortcomings likely underlie, at least in part, the unmet needs of patients with this disfiguring and potentially sight-threatening disease. The persistence of important and bothersome disease manifestations clearly impacts activities of daily life, regardless of disease duration. It is essential that physicians and other healthcare professionals who are treating TED become more familiar with patient experiences such as those described here. Results from our survey should invigorate the importance of long-term follow-up and management of patients. Their healthcare providers need to better accommodate the needs of these patients and improve their journey with TED."

As a supplement to the original article, Kimberly Dorris and GDATF Founder Dr. Nancy Hord Patterson recorded two webinars highlighting the survey results. GDATF also reviewed hundreds of narrative responses and collated them by category. To view the videos or the narrative responses, please visit the GDATF website at https://gdatf.org/resources/ted-survey-2022-2023/.

To view the original Frontiers in Endocrinology journal article, please visit the link below.
https://www.frontiersin.org/journals/endocrinology/articles/10.3389/fendo.2023.1283374/full

This project was funded by an educational grant from Amgen, Inc., formerly Horizon Therapeutics. Amgen, Inc. was not involved in the study design, collection, analysis, interpretation of data, the writing of this article or the decision to submit it for publication.

Dr. Nancy Hord Patterson, Founder, and Kimberly Dorris, Executive Director, GDATF, during the webinar.



Treatment of Hypothyroidism — Changes in Appetite and Food Intake

BY BJARKE RØSSNER MEDICI AND FILIP KRAG KNOP, BOTH FROM THE MEDICAL DEPARTMENT, HERLEV HOSPITAL AND THE CENTER FOR CLINICAL METABOLIC RESEARCH, GENTOFTE HOSPITAL*

When a patient is treated for hypothyroidism, there is often an expectation of weight loss, as hypothyroidism is often associated with obesity. A 2023 study examined appetite and food intake after starting treatment with Levothyroxine.

There is a lot of attention on health and obesity. It plays a major role in the media – which is also reflected in the sales of weight loss products. And when it comes to thyroid disease, weight is often discussed.

Hypothyroidism is often associated with being overweight, and the English term "slow metabolism" indicates that you gain weight if you have the disease. It therefore seems logical to expect weight loss when treating the disease.

But what is true about these expectations about weight loss – and what does the research say?

It has previously been well documented that treatment of hypothyroidism with Levothyroxine (in the form of Eltroxin, Euthyrox or Tirosint) increases Basal Metabolic Rate (BMR). The BMR is the basal burning of calories that the body has without physical activity. However, previous studies indicate that the weight change at the start of treatment with Levothyroxine is very small – and that the weight loss does not consist of fat, but mainly of fluid.

New Danish Research

To gain more insight into unrealized expectations of weight loss, we designed and conducted a new Danish study through 2023 with the participation of 18 women with severe hypothyroidism.

The 18 women with untreated hypothyroidism were examined before and during treatment with Levothyroxine. In a control group we had 18 healthy women who matched the other group in BMI and age.

The study mainly looked at changes in appetite and food intake after the start of treatment with Levothyroxine.

Appetite was assessed by having the patients mark a scale 13 times during the study day depending on how hungry, thirsty, full, etc. they felt.

Food intake was assessed at an ad libitum (without restriction) meal at the end of each study day.

Thus, the primary foci of the study were appetite and food intake, and secondarily it looked at changes in body composition, BMR, hormones related to appetite and food intake, gastric and gallbladder emptying, physical activity and blood sugar control.

The study took place over three study days for the 18 women and a single study day for the 18 women in the control group.

The patients' first day of study took place immediately after diagnosis, but before they started taking Levothyroxine. The second day of study took place once Thyroid Stimulating Hormone (TSH) had normalized, and the third day of study took place after approximately six months of treatment.

At the beginning of the study day, participants arrived fasting, and initial examinations and measurements of blood samples and appetite were taken. They were then given a standardized drink meal containing Panodil to monitor gastric emptying. Continuous measurements of appetite, BMR, and blood samples were taken over the next four hours. Finally, a large bowl of pasta Bolognese was served as an ad libitum meal, with participants allowed to eat as much as they wanted.

(continued on page 17)

Changes in Appetite and Food Intake *(continued from page 16)*

Results

Our results showed that patients experienced significantly increased appetite at the start of treatment with Levothyroxine. More pasta Bolognese was eaten in the ad libitum meal after the start of treatment, but this was not statistically significant.

As seen in other studies, we saw a significant increase in resting energy expenditure, but no change in the amount of body fat.

The patients' daily activity appeared to have increased after the start of treatment, and gallbladder emptying was also improved.

There were no noticeable changes in hormones related to appetite and food intake – and the change in blood sugar levels was also very small.

Discussion

In the 18 patients with hypothyroidism, there was a significant increase in BMR, but fat mass remained unchanged. The patients had severe hypothyroidism before treatment, yet the change in ad libitum food intake was not large.

We saw a noticeable increase in hunger after starting treatment. Any increase in resting metabolic rate should result in a loss of fat mass unless burning of calories increases due to more food intake. This therefore suggests that treating hypothyroidism increases appetite and food intake, which prevents theoretical weight loss. However, we do not know exactly which mechanisms lead to this increased feeling of hunger and the lack of weight loss.

We saw no clear changes in the classical hormones related to appetite and food intake. The patients' physical activity was increased, which should increase the change in fat mass or food intake. Thus, the mechanism behind the change in appetite remains uncertain, but it is likely that the increased appetite is due to increased energy turnover, as seen in untreated patients with hyperthyroidism. Patients with hyperthyroidism often have a large appetite along with an increase in resting metabolic rate. In hyperthyroidism, the increased food intake is burned, and patients often lose weight before treatment begins. However, when the metabolism is normalized, the lost weight comes back.

Overall, the study emphasizes that physicians and patients should not expect major weight loss when initiating treatment for hypothyroidism, as the increased resting metabolic rate is unlikely to have an effect due to the corresponding increased appetite.

The effectiveness of the treatment is well documented in relation to other symptoms of hypothyroidism – but one should not expect a reduction in body fat percentage.

Original article

Medici et al. Effects of levothyroxine substitution therapy on hunger and food intake in individuals with hypothyroidism. Endocrine Connections. August 2023.

Quote: This therefore suggests that treating hypothyroidism increases appetite and food intake, which prevents theoretical weight loss through increased energy expenditure.

*Employed by Novo Nordisk from 1/12-2023.

News from the Thyroid Field

Just Diagnosed: What Now?

Expectation Management with Hyperthyroidism

Feeling restless, heart palpitations, and weight loss: too much thyroid hormone puts your body into overdrive. Not treating it is not an option, and several treatments are available. What should you know if you've just been diagnosed, and what can you do yourself?

ESMEE KOK

This article was first published by Schildklier Organisatie Nederland, magazine Schild, June 2024, pg. 14-17.

It is written for the situation in the Netherlands.

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Too much thyroid hormone, also known as hyperthyroidism, is usually caused by Graves' disease.[1] An autoimmune disease in which antibodies against the TSH receptor are produced.[1,2] A multinodular goiter, an enlarged thyroid with multiple nodules, can also cause excess hormone production. Even a single nodule can produce too much thyroid hormone; this is called a hot nodule. Lastly, in rare cases, there can be a central cause. This involves a problem with the pituitary gland, not the thyroid. Treatment depends on the cause and the patient's situation and is managed by a specialist.[3-5]

(continued on page 18)

Just Diagnosed *(continued from page 17)*

What Can You Expect?

Treatment depends on the cause. To investigate this, your healthcare provider may, for instance, determine TSH receptor antibodies for diagnosing Graves' disease. An ultrasound or scintigraphy of the thyroid can reveal if there are hormone-producing nodules.[1,3,4]

Graves' disease is usually treated with thyroid inhibitors such as thiamazole, carbimazole, or propylthiouracil (PTU). There are two methods for this. In the block and replace method, you take a high dose of thyroid inhibitor to completely stop the thyroid. Additionally, you take thyroid hormone to compensate for the resulting deficiency. Another option is monotherapy, also known as titration. Here, you take just enough thyroid inhibitor to get your levels within the reference range and be symptom-free. Both treatments are equally effective in bringing the thyroid to rest (remission).[3,4] However, both have pros and cons, and in individual cases, one treatment may be better than the other.[1] With treatment, the FT4 level drops first. Even with a normal FT4, it can take another 3 months for TSH to normalize.[3] After 12 to 18 months of good levels, treatment stops, and you see if the thyroid works properly again. For 40 to 50% of patients, this results in long-term good thyroid levels.[3,4] If hyperthyroidism returns, treatment needs to be restarted. Thyroid inhibitors can be chosen again, but depending on how long the thyroid was in remission, your healthcare provider may also recommend radioactive iodine or surgery.[1,3,4]

Hormone-producing nodules can be surgically removed, with radiofrequency ablation, or with radioactive iodine. Thyroid inhibitors are not recommended because they would need to be taken for life.[1,3,4]

What Can You Do Yourself?

Educate yourself about the treatment options and get well-informed by your doctor. Knowing the treatment options, understanding how they work, and whether there is a preferred treatment for your situation1 can help you make an informed choice. Discuss your symptoms with your doctor, especially eye complaints, palpitations, and fever. Eye complaints can indicate Graves' orbitopathy, which affects 1 in 5 Graves' patients. Starting treatment quickly is important. Beta-blockers can reduce symptoms for palpitations or heart complaints.[1,2,4,5]

Contact a doctor immediately if you experience fever along with palpitations, nausea, vomiting, and diarrhoea. This can indicate a thyroid storm, a rare life-threatening form of hyperthyroidism requiring hospital treatment.[6]

Too much thyroid hormone takes a toll on your body. It's like running a marathon at rest. Listen to your body and don't push your limits. Be cautious with intense exercise during treatment. Excess thyroid hormone can also cause psychological symptoms, including mood disorders. Discuss these symptoms with your close ones for more understanding. Finally, the effect of too much hormone on your body doesn't disappear within a few days after starting treatment. Setting up treatment with thyroid inhibitors can also cause symptoms. Every thyroid patient is different, and only you know how you feel. Take your symptoms seriously and give your body the time and space to recover.

Schildklier Organisatie Nederland (Thyroid Organisation of the Netherlands)

On the SON website schildklier.nl, you will find reliable, evidence-based information (in Dutch language) about all thyroid conditions. There are dossiers and webinars on specific complaints or issues such as psychological symptoms, heart problems, thyroid cancer, pregnancy, physical activity and sports, created in collaboration with leading doctors.

Thyroid Levels

- **TSH:** In primary thyroid disorders, TSH is a good indicator of whether the amount of thyroid hormone in your blood is sufficient for your body. However, after starting the thyroid inhibitor, it takes about 12 weeks for TSH to normalize. Therefore, undetectable TSH with normal FT4 values is normal in the initial tests.
- **Free T4:** Most T4 hormone is bound to carrier proteins in the blood. The levels of these carrier proteins can change (for example, due to the menstrual cycle or contraceptive use), which can cause variations in total T4 levels. Research shows that free T4 (FT4) correlates with symptoms.
- **Free T3:** Sometimes doctors also measure free T3 (FT3) in hyperthyroidism cases. This is done to determine if there is Graves' disease or thyroiditis. It also happens when TSH is undetectable with normal FT4 values; in this case, FT3 is measured to check for T3 toxicosis, which is hyperthyroidism with only elevated (F)T3.[1,3]
- **TSH Receptor Antibodies:** These antibodies are the cause of Graves' disease and are also known as TSI, TRAb, TSAb, or TSH-R antibodies.

Blood Tests

Each lab establishes its own reference values based on the equipment and methods they use. Therefore, only compare your values with the reference values of the lab where your blood was tested. When using block

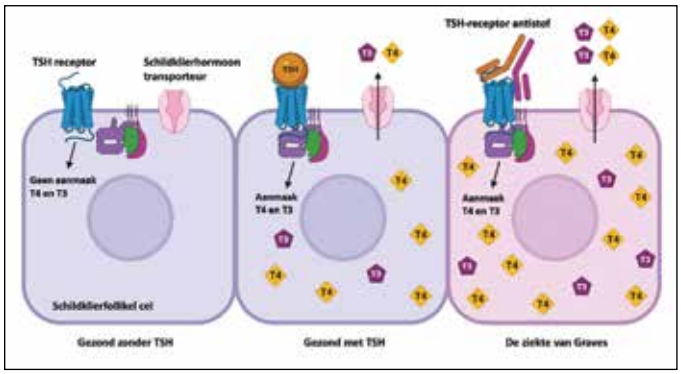
(continued on page 19)

Just Diagnosed *(continued from page 18)*

and replace, have your blood drawn before or more than 4 hours after taking levothyroxine. After intake, FT4 temporarily rises due to the absorption of levothyroxine.

How Does Graves' Disease Work?

In Graves' disease, antibodies against the TSH receptor are produced. In healthy individuals, TSH binds to this receptor, activating it and causing the production and release of thyroid hormone. In Graves' disease, the antibodies bind to the TSH receptor, causing it to remain active and the thyroid to produce and release too much hormone.[1,2]



Advantages and Disadvantages of Treatments

In most cases, all treatments are equally effective.[1,3,4] However, personal circumstances or preferences can make one or more treatments more suitable. For example, in cases of active Graves' eye disease, high TSH receptor antibodies, liver disease, heart failure, or an enlarged thyroid pressing on the windpipe.[1,3,4]

Block & Replace

Advantages:

- 40% to 50% chance of long-term remission
- Levels stabilize faster within reference values
- Fewer check-ups
- Doctors have extensive experience with block and replace

Disadvantages:

- Two relatively high-dosed medications
- 1-5% chance of side effects
- Not suitable during pregnancy
- No remission for nodules or (multinodular) goiter

Titration

Advantages:

- 40% to 50% chance of long-term remission
- One low-dosed medication

Disadvantages:

- 1-5% chance of side effects
- Levels may fluctuate; not everyone achieves stability
- More frequent blood tests
- No remission for nodules or (multinodular) goiter

Radioactive Iodine

Advantages:

- Results within a few months
- Improvement for pressure on the oesophagus and/or windpipe

Disadvantages:

- Risk of hypothyroidism (30-60% after 1 year, 50-80% after 10 years)
- Not suitable during or 6 months before pregnancy
- Can worsen Graves' eye disease
- Hospitalization needed for high doses
- Lifestyle restrictions for the first few days
- Side effects like sore throat and salivary gland issues

Radiofrequency Ablation

Advantages:

- Less invasive than surgery
- No or minimal scarring

Disadvantages:

- Only suitable for a single nodule
- Not effective for all or multiple nodules
- Sometimes the nodule doesn't shrink enough
- Risk of hypothyroidism, though lower than with radioactive iodine

(continued on page 20)

Just Diagnosed *(continued from page 19)*

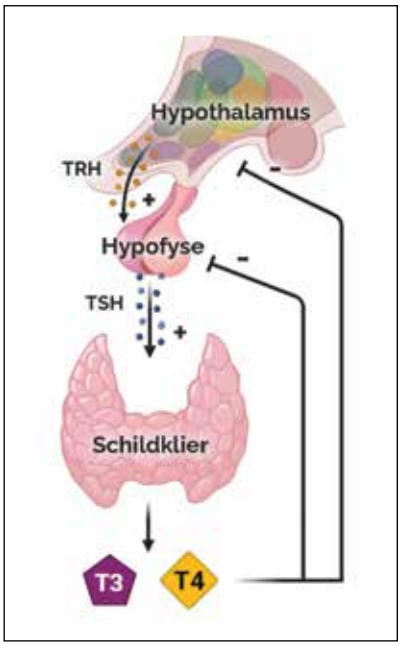
Surgery

Advantages:

- Quick results
- Improvement for pressure on the oesophagus and/or windpipe
- Better outcome for significantly enlarged thyroid

Disadvantages:

- Hypothyroidism if the entire thyroid is removed
- Risk of hypothyroidism (3% after 1 year, 50% after 10-20 years) if half the thyroid is removed
- Risk of parathyroid problems
- Risk of vocal cord issues
- Surgery risks such as infection



How Does the Thyroid Work?

The hypothalamus and pituitary gland in the brain regulate the thyroid. The hypothalamus receives information from the body and brain about the levels and needs for thyroid hormone. It produces TRH, which signals the pituitary gland. The pituitary gland measures the levels of TRH and thyroid hormone and then produces TSH. TSH (thyroid-stimulating hormone) causes the thyroid to produce T4 and T3 hormones. When this system functions properly, it is very sensitive. A small change in FT4 leads to a significant change in TSH. In hyperthyroidism, you have low or undetectable TSH and high FT4. High TSH and high FT4 indicate a problem with the pituitary gland. A doctor will use these values to assess thyroid function.

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SON Schildklier Organisatie Nederland

https://schildklier.nl/

Postoperative Diagnostics and Treatment of Well-Differentiated Thyroid Tumors

Professor Tomislav Jukić, Head of Dpt of Nuclear Medicine, Dpt of Oncology and Nuclear Medicine, Sisters of Charity UHC, Zagreb, Croatia

Roko Granić MD, Nuclear Medicine Specialist, Dpt of Oncology and Nuclear Medicine, Sister of Charity UHC, Zagreb, Croatia

Well-differentiated malignant thyroid tumors are divided into papillary and follicular tumors. These are the most common malignant tumors of the thyroid and, in general, the most common malignant endocrine tumors. Croatia holds the infamous fourth place in Europe regarding the frequency of malignant thyroid tumors. The frequency of thyroid tumors has been increasing in the last few decades mostly due to improved diagnostics. Modern ultrasound devices differentiate even the smallest of thyroid nodules, and fine needle aspiration biopsy (FNAB) of the nodules differentiate between potentially malignant and benign nodules. If a nodule is suspected of malignancy it requires swift surgical treatment. Despite the increased frequency, mortality from malignant thyroid tumors has not increased but is in a continuous slight decline, probably due to improved diagnostics by detecting small tumors in the earlier stages of the disease as well as modern modes of targeted therapy for advanced forms.

Differentiated malignant thyroid tumors are treated by surgical removal of the thyroid gland with the tumor itself, followed by treatment with radioactive iodine-131 and the introduction of synthetic replacement treatment thyroid hormone levothyroxine (L-T4). After surgical removal of the thyroid, patients are referred to postoperative diagnostic processing that consists of laboratory tests, neck ultrasound and imaging of the whole body with radioactive iodine-131.

Postoperative laboratory tests include the determination of a specific tumor marker called thyroglobulin. Thyroglobulin is normally secreted by thyroid follicular cells into the bloodstream, but also by the cells of well-differentiated thyroid tumor. Thyroglobulin is normally found in the blood of all people who have a thyroid, and after its surgical removal, the thyroglobulin value should be low, but rarely unmeasurable because more or less thyroid remnant tissue is left depending on many preoperative and surgical factors. High serum value of the tumor marker thyroglobulin after thyreoidectomy could be a marker of possible extrathyroid extension of the disease. In addition to thyroglobulin, thyroglobulin antibodies (Anti-Tg) in the serum are also always tested postoperatively. If there are Anti-Tg antibodies present in the serum, then the laboratory value of thyroglobulin is unreliable because the presence of these antibodies affects the determination of thyroglobulin. Thyroglobulin antibodies should be considered as a tumor marker in themselves because their presence points to residual thyroid tissue or the presence of a well-differentiated thyroid tumor or metastasis.

Testing serum levels of thyroid hormones and thyrotropin (TSH) is an important component of the postoperative diagnostics and treatment. After surgical removal of the thyroid gland, a substitute synthetic hormone L-T4, is introduced to patients in a dose that meets the individual needs. Dosages of L-T4 mainly depends on muscle mass, body weight and physical activity. In younger patients, TSH is maintained towards the lower levels of the reference range (from 0.5 to 2.5 mU/L), and in elderly patients at the upper limit of the reference range (from 2.5 to 4.0 mU/L). To assess the dose, it is necessary that the patient takes the prescribed dose of L-T4 for at least 6 weeks to restore balance. Patients treated for well-differentiated thyroid tumor often take a slightly higher dose of L-T4 than necessary, that is called a suppressive treatment. With suppressive treatment, we keep the TSH low and in that way the tumor cell growth is prevented or at least slowed.

An important diagnostic test to determine the extent of differentiated thyroid cancer (DTC) is whole body imaging with radioactive iodine-131, called scintigraphy of the whole body with iodine-131.

DTCs are characterized by the accumulation of iodine, therefore radioactive iodine-131 is used in their diagnostics as well as treatment.

Imaging with iodine-131 is performed under a gamma camera two to three days after patient that underwent thyreoidecomy received (drank) a small diagnostic dose of iodine-131 or a few days after receiving a therapeutic dose of iodine-131. The whole body and especially the area of the front neck region are

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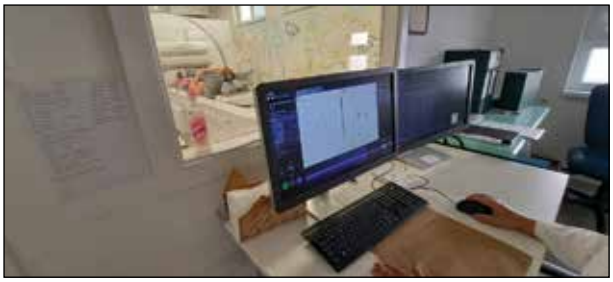
Postoperative Diagnostic Treatment *(continued from page 21)*



examined and if necessary a layered three-dimensional imaging of regions of interest with a possibility of computerized tomography (CT) with low doses of radiation is performed so the image can be interpreted more precisely.

For the proper execution of whole body scintigraphy with iodine-131 and the therapeutic application of iodine-131 a high TSH level is required, i.e. a state of hypothyroidism, which is achieved by stopping treatment with L-T4 lasting about 4 weeks prior to scintigraphy. Patients that can be endangered with hypothyroidism (i.e. cardiac patient or patient with other malignancy) can receive human recombinant TSH that enables them to stay on their L-T4 treatment throughout the diagnostic and therapeutic treatment.

A diet with a reduced intake of iodine, which limits the intake of salt, salty foods and foods rich in iodine such as seafood, shellfish, milk and milk products, eggs and iodine pills is introduced 10 days before scintigraphy or iodine-131 treatment.

With iodine-131 whole body scintigraphy it can be determined if a thyroid remnant or thyroid cancer metastases (still) exists in the neck area. Distant metastases (usually in the lungs, bones or lymph nodes) are fortunately very rare but they also can be easily determined with Iodine-131 whole body scan.

Most DTC metastases accumulate iodine-131, so they can be treated ("what you can see, you can treat!"). Iodine-131 destroys the remaining tissue by internal irradiation of the thyroid gland and metastases of differentiated thyroid cancer. Targeted accumulation in metastases slowly destroys them, and the therapy can be repeated several times at intervals of 6 months to a year.

The application of iodine-131 is simple in the form of a capsule that is swallowed or a liquid that is drank. The Iodine-131 therapy has no significant unwanted side-effects. It is necessary for the patient to be in hospital isolation conditions after receiving iodine-131 therapy for several days depending on the radiation dosage he received. The isolation of a patient is essential for the protection of other persons, especially small children and pregnant women, who are most sensitive to the effects of radiation. Isolation is most often carried out in special hospital conditions – isolation rooms in nuclear medicine departments. Patients who received therapy with iodine-131 must increase fluid intake, have regular bowl movement and increased salivation (by sucking on a lemon, drinking lemonade, chewing a chewing gum or a sour candy). These measures are necessary to encourage faster excretion of iodine-131 from the body. Pregnant or lactating women are prohibited to receive iodine-131 therapy, so it is mandatory to rule out these conditions before proceeding with the treatment. The pregnancy is discouraged and should be postponed for at least 6 months and preferably one year after iodine-131 treatment.

For men conception should be delayed for at least 4 months.

Iodine-131 scintigraphy of the whole body is not performed routinely, but only postoperatively and on the first hospital visit after iodine-131 therapy when it is most often confirmed that there are no signs of thyroid remnant or metastatic tissue. In most cases clear whole body scan is accompanied by low or unmeasurable tumor marker thyroglobulin levels.

An important diagnostic tool in patients with a well-differentiated thyroid cancer is neck ultrasound examination. It is the most sensitive test for detection of enlarged and/or morphologically changed lymph nodes of the neck and return of the tumor in the thyroid bed.

Metastases of a well-differentiated thyroid cancer are most commonly found in the neck and can be detected in as many as 20-50% of patients. To confirm metastasis in the lymph node or thyroid bed, it is necessary to do a fine needle aspiration biopsy (FNAB) and take a cytological sample for analysis (cytological sample is also tested for thyroglobulin levels which if increased proves the presence of metastatic tissue within the lymph node). Positive thyroglobulin in the lymph node aspirate significantly improves the sensitivity of FNAB.

Ultrasound of the neck with FNAB if needed, plays an important preoperative role because in this way, the scope of the (thyroid/neck) surgery is more carefully planned – the affected lymph nodes are readily removed with the thyroid and the dissection is contained.

(continued on page 23)

Postoperative Diagnostic Treatment *(continued from page 22)*

Oncological followup consists of the tumor marker thyroglobulin test, thyroid hormone and TSH, as well as neck ultrasound, which is performed every 6 months to a year.

Thanks to modern diagnostics of well-differentiated malignant thyroid tumors and effective treatment, with experienced and excellent surgeons, as well as treatment with iodine-131, we achieve great results in the treatment of these malignant tumors with extremely low mortality and morbidity rates that improves patients' well-being and speeds up their recovery so they can return to their everyday activities.

News from the Thyroid Field

Protecting Parathyroid Glands

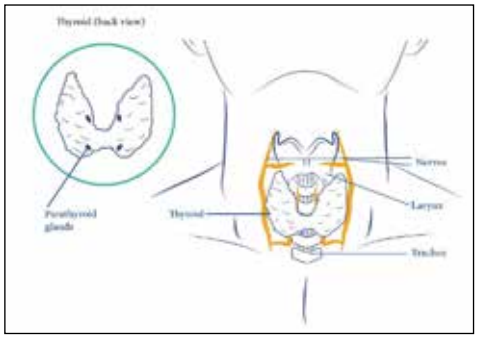
AGNIESZKA STRZEMBOSZ MD, PHD, MEDTRONIC ENT INT'L MEDICAL AFFAIRS DIRECTOR

Complications from thyroid and parathyroid surgery are usually rare, as surgeons take great care to avoid them. They also use novel technologies to minimize risks. Intraoperative nerve monitoring helps surgeons reduce potential damage to the nerves, with the objective of avoiding voice changes and difficulty swallowing.[1] Bleeding can be reduced by using power-generating devices during surgery.[2-4]

Another critical complication that can potentially have a devastating impact on a patient's quality of life is a disturbance in calcium levels.[5] The tiny parathyroid glands near the thyroid gland control calcium in the blood.

The Parathyroid Gland Anatomy

The parathyroid glands are four small pea-shaped glands located behind the butterfly-shaped thyroid gland in the neck. Typically, there are two on each side, one above and one below. Despite their small size (about the size of a grain of rice), these glands play a crucial role in controlling calcium levels in the blood.



Hypocalcemia and its Symptoms

If the parathyroid glands are damaged during surgery, it can result in low calcium levels, known as hypocalcemia. This condition can cause symptoms such as tingling in the fingers, muscle cramps, restlessness, and a cool feeling in the mouth resembling the sensation of eating a mint.[6] Patients may also experience cognitive difficulties, such as mental fog and difficulty concentrating. Prolonged low calcium levels can lead to dry, flaky skin, brittle nails, and coarse hair.[7]

While only a small number of patients develop long-term symptomatic hypocalcemia, the associated mental, social, emotional, and physical effects are significant.[8-9]

Parathyroid Gland Autofluorescence

The main strategy to reduce the risk of postoperative hypocalcemia is to improve the identification of the parathyroid glands during surgery.[10]

Parathyroid autofluorescence detection is an innovative technique used during thyroid and parathyroid surgery to confirm the localization of the parathyroid glands. This method utilizes the natural autofluorescence properties of parathyroid tissues when stimulated with near-infrared (NIR) light.[11]

Imagine the parathyroid glands as small glowing objects hidden inside the neck. During surgery, surgeons need to find these tiny glands without harming them. To do this, surgeons can use a special light that makes the parathyroid glands light up, similar to how white clothes glow under a blacklight. This glow helps surgeons see exactly where the glands are, so they can avoid damaging them while they work. It's like using a flashlight to find something in the dark – the light makes it much easier to see what you're looking for.

Recently, in Europe, the PTeye™ (parathyroid eye) technology has become available for thyroid and parathyroid surgery. Its most important role is to help surgeons in the identification of parathyroid tissue, with

(continued on page 24)

Protecting Parathyroid Glands *(continued from page 23)*

the objective to avoid these tiny glands being accidentally removed during thyroid surgery.[12]

Studies have shown that surgeons using this technology are more confident in identifying parathyroid glands. In 88.9% of cases, the procedure was beneficial in confirming parathyroid tissue.[13] This technology is particularly useful when the location of the glands is unclear due to anatomical variations, specific diseases, or inconclusive pre-surgery exams.[14]

This article has been designed for high level information purposes and could not represent or replace any medical opinion the patient must receive, nor represent an exhaustive view of the medical topic addressed. Always talk to your doctor or other qualified health provider about your medical condition and available treatments. If you have any questions, please contact your treating physician.

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Viridian Therapeutics REVEAL

Viridian Therapeutics, Inc. a biotechnology company focused on discovering and developing potential best-in-class medicines for serious and rare diseases, reported details of its plans to initiate a phase 3 clinical trial program for its SC VRDN-003 product candidate for patients with moderate-to-severe thyroid eye disease (TED).

Phase 3 Clinical Trials in Active and Chronic TED

Viridian is planning to initiate two randomized, double-masked, placebo-controlled phase 3 clinical trials designed to evaluate the efficacy and safety of subcutaneously administered VRDN-003 in patients with active and chronic TED, named REVEAL-1 and REVEAL-2, respectively. These clinical trials are expected to initiate in August 2024.

In REVEAL-1, approximately 84 patients will be randomized in a 1:1:1 ratio to receive VRDN-003 SC or placebo every 4 weeks or every 8 weeks. Patients will receive an initial 600mg loading dose given as two 300mg injections, followed by single injections of 300mg thereafter for a total of 6 administrations in the 4-week dosing regimen and a total of 3 administrations in the 8-week regimen. In REVEAL-2, approximately 126 patients will be randomized in the same manner for the same dosing regimens. The primary endpoint in each clinical trial will be proptosis responder rate, based on the achievement of at least 2mm improvement in proptosis from baseline at week 24, versus placebo. Subsequently, patients will be followed for an additional 28 weeks. Additional outcome measures in each trial will include changes from baseline in proptosis, clinical activity score (CAS) and diplopia.

"The current standard of care in TED requires 8 intravenous doses, representing a significant burden for patients," said Tom Ciulla, Viridian's Chief Medical Officer. "Subcutaneous VRDN-003 could transform the treatment experience for patients with TED."

Viridian anticipates topline data for both clinical trials to be available in the first half of 2026 and to file a BLA by the end of 2026. The company plans to launch VRDN-003 with a commercially available autoinjector pen.

About VRDN-003

VRDN-003 is a potential best-in-class, subcutaneously administered anti-IGF-1R antibody in development for TED. VRDN-003 has the same binding domain as VRDN-001, was engineered to have a longer half-life, and acts as a full antagonist of IGF-1R. IGF-1R inhibition is the only approved mechanism of action that has been clinically and commercially validated for TED and has shown to be highly effective in treating the disease.

Phase 1 results in healthy volunteers showed a VRDN-003 half-life of 40-50 days which is 4-5x the half-life of VRDN-001. Further, pharmacokinetic modeling predicts that convenient dosing regimens of VRDN-003 (e.g., a low volume subcutaneous injection once every 4 or 8 weeks) could achieve exposure levels of VRDN-003 that are equivalent to those of VRDN-001 that produced clinically meaningful results in TED patients in a phase 2, proof-of-concept clinical trial.

About Viridian Therapeutics

Viridian is a biopharmaceutical company focused on engineering and developing potential best-in-class medicines for patients with serious and rare diseases. Viridian's expertise in antibody discovery and protein engineering enables the development of differentiated therapeutic candidates for previously validated drug targets in commercially established disease areas.

Viridian is based in Waltham, Massachusetts. For more information, please visit:

www.viridiantherapeutics.com

Full press release:

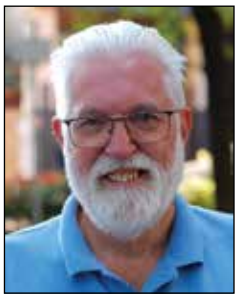
https://investors.viridiantherapeutics.com/news/news-details/2024/Viridian-Therapeutics-Announces-Details-of-Subcutaneous-VRDN-003-Phase-3-Clinical-Program-for-Patients-with-Active-and-Chronic-Moderate-to-Severe-Thyroid-Eye-Disease/default.aspx

VIRIDIAN

Book Review – Yodo, Deficiencia Nutricional y Salud Pública

"Iodine Defficiency and Public Health"

PETER LAKWIJK



The book *"Yodo, Deficiencia Nutricional y Salud Pública"* by Dr. Ignacia Ramírez Aguirre, available in Spanish, addresses the critical issue of iodine deficiency and its impact on public health in Bolivia. A summary of the book:

Title: Yodo, Deficiencia Nutricional y Salud Pública

Author: Dr. Ignacio Ramírez Aguirre

Overview

The book explores the essential role of iodine in human health, the consequences of iodine deficiency, and the public health measures needed in Bolivia to combat this issue. It is particularly relevant for healthcare professionals and policymakers who are involved in nutritional and public health initiatives.

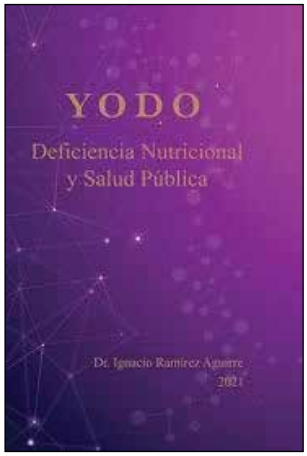
Key Points

1. **Importance of Iodine:**
   - Iodine is a crucial nutrient required for the production of thyroid hormones, which regulate metabolism, growth, and development.
   - Adequate iodine intake is essential for proper brain development, especially in foetuses and young children.
2. **Consequences of Iodine Deficiency:**
   - Iodine deficiency can lead to various health problems, including goiter (enlarged thyroid gland), hypothyroidism, and developmental delays in children.
   - Severe deficiency during pregnancy can cause cretinism, a condition characterized by severe physical and mental impairment.
3. **Prevalence and Public Health Impact:**
   - The book discusses the prevalence of iodine deficiency in different regions, with a focus on Ecuador and Latin America.
   - It highlights the significant public health burden caused by iodine deficiency, affecting millions of people and leading to economic losses.
4. **Strategies to Address Iodine Deficiency:**
   - Dr. Ramírez outlines various public health strategies to combat iodine deficiency, such as iodization of salt, public education campaigns, and monitoring iodine levels in populations.
   - The book emphasizes the importance of collaboration between governments, health organizations, and communities to ensure effective implementation of these strategies.
5. **Case Studies and Research:**
   - The book includes case studies and research findings that illustrate the impact of iodine deficiency and the success of intervention programs.
   - It provides practical recommendations for healthcare providers to identify and treat iodine deficiency in their patients.

Conclusion

"Yodo, Deficiencia Nutricional y Salud Pública" is a comprehensive resource that underscores the importance of addressing iodine deficiency as a public health priority. It offers valuable insights and practical solutions to improve iodine nutrition and overall health outcomes.

For more detailed information, you can access the full text of the book through the link https://issuu.com/sociedadbolivarianadelecuador/docs/libro_yodo_dr._ramirez



A Perspective on the Treatment Landscape in Graves' Disease

In this Q&A, Pete Salzmann, M.D., MBA, Chief Executive Officer at Immunovant shares his thoughts on existing challenges and opportunities in the management of Graves' disease.

What do you see as the key unmet needs in Graves' disease?

We have limited treatment options for Graves' disease, which remains the leading cause of hyperthyroidism. I think challenge number one is that Graves' disease is an autoimmune condition, yet existing therapies don't address the underlying disease driver. In Graves,' harmful immunoglobulin G (IgG) autoantibodies bind to and activate thyroid-stimulating hormone receptor (TSHR), stimulating excess thyroid hormone production. The first line treatment, anti-thyroid drugs (ATDs), focus on the resulting hormone imbalance, while definitive options destroy the thyroid.

The second challenge is that ATDs don't work for everyone – some patients don't achieve normal thyroid function despite ongoing ATD treatment at standard doses. It's difficult for some patients to comply with optimal dosing due to tolerability and safety issues, particularly with long term use. Patients with very high autoantibodies, a large goiter, or high thyroid levels may not be well-controlled at standard doses.[1]

Additionally, some patients struggle to maintain normal thyroid levels over time despite treatment with ATDs; approximately 50 percent of patients relapse after initial treatment, and there are well-documented safety and tolerability concerns with long-term use. Patients who remain thyroid hormone receptor antibody (TRAb) positive are associated with a higher rate of relapse following ATD discontinuation.[2] This means that a meaningful proportion of patients are unable to achieve normal hormone function and continue to struggle with persistent hyperthyroidism and the associated symptoms.

Finally, in circumstances where patients are not well controlled or unable to tolerate optimal dosing with ATDs, they are left with definitive options, such as radioactive iodine (RAI) and thyroidectomy. Both of these procedures present the risk for potential complications and they often lead to irreversible hypothyroidism, and the need for lifelong thyroid hormone replacement therapy. A treatment that could address the underlying autoimmune component of Graves' disease could offer new options to patients before requiring a definitive procedure.

The treatment landscape for Graves' disease has been unchanged for a long time. Why is change needed now?

First, treatment options have been largely unchanged for the last 70 years; science and our understanding of Graves' disease has advanced a lot in that time. And, importantly, the need for medical management of Graves' disease has increased. A recent global survey of endocrinologists and allied specialists showed a significant shift in practice: in 2023, only 11.1 percent of North American respondents would recommend RAI therapy in uncomplicated Graves' disease, a drastic decline from 69 percent in 1990.[3] Among all respondents, a desire to avoid hypothyroidism, to achieve remission and to avoid radiation exposure were the top reasons providers preferred ATD therapy over RAI.[4] However, we know ATDs may not achieve remission for all and have considerable drawbacks. Further innovation in Graves' disease is clearly needed.

How do you hope that GD management will change in the future?

FcRn-targeted therapies being studied by Immunovant may offer a new approach to treat Graves' disease by focusing on the underlying autoimmune condition. By reducing harmful IgG autoantibodies via FcRn inhibition, we have the potential to improve outcomes and quality of life for people with the condition. To learn more about Immunovant's goal to reframe expectations in Graves' disease, visit Immunovant.com

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Seeking Thyroid Truths: A Guide for the Curious

PETER LAKWIJK

Dr. Petros Perros

"Seeking Thyroid Truths: A Guide for the Curious" by Dr. Petros Perros is a comprehensive resource aimed at patients with thyroid diseases, their carers, healthcare workers, and anyone interested in the thyroid. The book is structured to help readers navigate the complex landscape of thyroid-related information, offering practical advice on finding, accessing, and evaluating medical evidence.

The book begins with an introduction that sets the stage by discussing common misconceptions and biases that can hinder the search for thyroid-related truths. Dr. Perros emphasizes the importance of critical thinking and empirical knowledge in understanding thyroid conditions.

Key Sections:

1. Obstacles to Seeking Truth:
   - Discusses various cognitive biases and logical fallacies that can distort our understanding of thyroid issues.
   - Introduces concepts like Cromwell's rule, Popper's swans, and the illusory truth effect.
2. Thyroid Basics:
   - Explains the anatomy and function of the thyroid gland.
   - Covers common thyroid conditions, including hypothyroidism and hyperthyroidism, and their symptoms and treatments.
3. Evidence-Based Medicine:
   - Provides an overview of different types of clinical evidence, from case reports to randomized controlled trials.
   - Discusses the publication process and the architecture of medical papers.
4. Mining the Truth:
   - Guides readers on how to use academic search engines and other resources to find reliable thyroid information.
   - Warns against common pitfalls and misinformation.
5. Appraising the Evidence:
   - Offers a checklist for evaluating the quality of medical studies.
   - Discusses the importance of peer review, study design, and statistical methods.
6. Interpreting the Evidence:
   - Teaches readers how to interpret statistical data and understand the clinical significance of study results.
   - Emphasizes the balance between efficacy, safety, and cost-effectiveness in thyroid treatments.

Part Two:

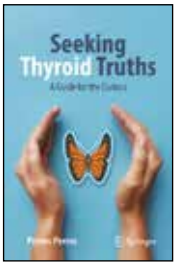
The second part of the book delves into certain aspects of hypothyroidism conditions and its management. It discusses the optimal range for thyroid function tests, the analogy between hypothyroidism and diabetes, and the public health implications of poorly controlled hypothyroidism.

Epilogue and Additional Resources:

The book concludes with a glossary of thyroid-related terms and further references for readers who wish to delve deeper into specific topics.

Dr. Perros, an experienced endocrinologist, combines his extensive clinical and research experience to provide a balanced perspective. He acknowledges the limitations of scientific knowledge and the value of patient experiences, aiming to bridge the gap between empirical evidence and individual patient needs. The book serves both as an informative guide and a reference manual, making it a valuable resource for anyone seeking to understand thyroid health better. Dr Perros has pledged all royalties from sales of the book to patient-centred thyroid research.

The book has not yet been released. You may pre-order it now and the book will be shipped when it is published on 15 Oct 2024.



Gail Devers, an Inspiration for All

Roko Granić

Gail Devers is best known as an American gold medalist, a star runner who won a gold medal in the 1992 Summer Olympics and two more in 1996 in Atlanta. From her very beginning, Devers wowed the crowds with her speed, strength, and agility, as well as her signature long, colorful fingernails.

TFI members first met this exceptional lady and sportswoman during the last annual gathering in Milano, Italy, in 2023 where she gave one of her hearwarmingly honest testimonies about overcoming thyroid disease and how it changed her life.

Gail Devers with Ulla Slama, Finland and Roko Granic, Croatia

In 1988 Devers had broken the American record in the 100 meter hurdles but the same year she almost dropped out of her first Olympics in Seoul, South Korea because she began feeling tired and had trouble training. "Every race that I ran, every practice, every time I warmed up was just taking more and more out of me", she said.

After that, things just got worse: she started to lose her hair, her fingernails became brittle, she lost weight, developed sores on her skin, suffered from insomnia, she had headaches and tremors, and started having memory problems. Also, her eyes were bulging and irritated.

Devers was so changed and upset by these symptoms that she actually covered her mirrors – the image in the mirror was not her any more, she despaired.

At first, the doctors she consulted had no answers for her problems.

Finally, Devers visited her old team physician at the University of California in Los Angeles, where she attended college, and this time was different. The doctor looked at her and said: "I can tell you're a walking thyroid disorder!"

She immediately broke into tears because after two and a half years, somebody finally saw what was going on.

Devers was diagnosed with Graves' disease, an autoimmune disease that's the most common cause of hyperthyroidism.

In Graves' disease, the immune system produces a thyroid stimulating antibody that makes the thyroid gland produce much more thyroid hormone than the body actually needs.

When Devers started treatment for Graves' disease, she was able to train and compete again, winning many gold medals in the Olympics and World Championships.

Yet again, something still wasn't right.

Devers still had eye pain and cloudy, blurred vision so she was constantly using eye drops. Sometimes it was so bad that that she couldn't even see the hurdles while racing.

It took Devers almost 30 years to find out she had a second condition that can accompany Graves' disease: Graves' ophthalmopathy, also known as thyroid eye disease (TED).

Thyroid eye disease is caused by inflammation in the tissues surrounding the eyes. Symptoms of thyroid eye disease can include redness, a feeling of grittiness in the eyes, eye watering, sensitivity to light, swelling or puffiness, bulging eyes, difficulty closing the eyes fully, double vision and, in prolonged and untreated cases, even vision loss.

After that long and tiring battle for her health, Devers decided she would make sure it doesn't take other people with Graves' disease as long as it took her to find out about thyroid eye disease.

"No one should have to go through what I went through. And the way to alleviate that suffering is education", Devers concluded.

As she was also at one time a relay runner, she emphasised how important it is to pass the baton from one person to the other, in this case the baton of knowledge and education about thyroid disease.

Devers' running goals helped her push through the challenges that Graves' disease and thyroid eye disease put in her path.

When we met this fascinating sportswoman, and the most gracious and generous person, in Milano last year, she was 57 years old, travelling half the world to meet with thyroid patients and their doctors, sharing her story and patiently posing for photos with her gold medals that represent not only the excellence in sports but also the resilience and determination to overcome the hurdles posed by every one of us in dealing with thyroid disease as patients or professionals.

Gail Devers, an inspiration for all of us!

Almost 60 local events providing Information and Support

International Thyroid Awareness Week took place throughout Finland, featuring content produced and distributed by the Thyroid Association of Finland and 59 local events organised by our local chapters. The range of materials that the association released included a press release, an informative infographic highlighting the prevalence of thyroid diseases relative to NCDs, and a psychologist's video lecture on achieving lasting lifestyle changes for better health. Additionally, downloadable materials were available to support both online and onsite participation. The association also provided recently updated brochures on hyperthyroidism, hypothyroidism, and parathyroid diseases, which the local member associations actively distributed.

Local events were organised to share information about thyroid and parathyroid diseases, provide peer support, and highlight local activities. Volunteers held the majority of these events. Local chapters held theme days in hospitals and health centres at OLKA service desks, which are platforms for non-profit organisations to provide information and support to hospital patients. Information desks were also held in shopping centres, city squares and pharmacies. Other events included a pharmacist's lecture, peer support evenings, a recreational peer-support walk, activities for families, and an exhibition of framed quotes from patients living with thyroid and parathyroid diseases.

We are delighted by the remarkable growth and expansion of the week within our member associations. With the efforts of local volunteers, we were able to share information and give support to a number of individuals living with thyroid and parathyroid diseases.

Kilpirauhasliitto

webinar: https://www.youtube.com/watch?v=3zYgd9sLBpQ — and the name and logo of the Organization, Thyroid Awareness Support Initiative (TASI)

THYROID AWARENESS & SUPPORT INITIATIVE

International Thyroid Awareness Week

(May 25th – 31st, 2024)

Nana Adwoa Konadu Dsane, Founder and President, TG

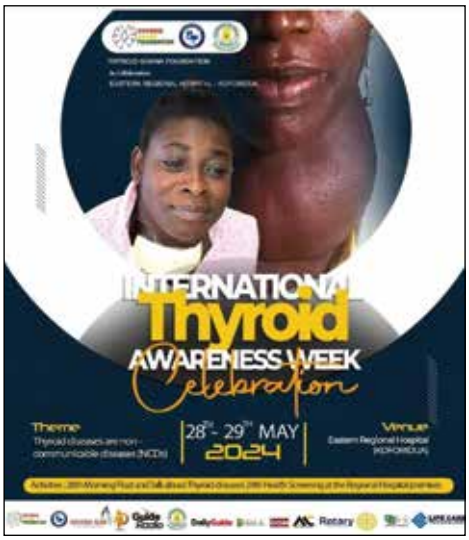
The Thyroid Ghana Foundation in collaboration with the Eastern Regional Hospital, Koforidua (ERH-K) celebrated the annual International Thyroid Awareness Week with a series of week-long activities under the theme: "Thyroid Diseases are Non-Communicable Diseases (NCDs)". During this period, 25th – 31st May 2024, events were held on the premises of the Eastern Regional Hospital, Koforidua.

The event had Academics, Medical practitioners, persons with thyroid disorders, beneficiaries of the subsidized thyroid surgeries, staff of ERH-K and some members of the public in attendance. Notable guests included the Head of Internal Medicine, Dr. Gyamgba (Chairperson of the event), the Clinical Director and Head of Surgery, Dr. Foster Amponsah, Heads of Department and Units, Medical practitioners, Staff, and Volunteers of TGF.

Float in the town of Koforidua

The event commenced with a float around town to raise the level of awareness to the locals. A webinar was then held after the float on the theme for the year: "Thyroid Diseases are Non-Communicable Diseases (NCDs)". This was by Dr. Foster Amponsah who spoke about the pathophysiology and care of thyroid conditions.

Presentation by Dr. Foster Amponsah



The benefits of certain herbs and spices that keep the body healthy were emphasized. This was followed by a screening exercise for suspected and existing persons who could not afford the healthcare fee. This was done to assess the level of their condition as these persons had stopped clinical attendance due to financial constraints. During the event, founder and president of TGF, Nana Adwoa Konadu Dsane mentioned in her speech how inspiring and beautiful the journey has been despite the challenges faced. She expressed gratitude to everyone who supported in diverse ways for the successes attained over the years.

Dignitaries and participants that honoured the event.

International Thyroid Awareness Week Is Back

Maria D'Aquino, HealthCom Consulting
Anna Maria Biancifiori, President CAPE
Giulia Giombolini, Secretary CAPE

May 20-25

Chronic Thyroid Diseases: More Information, Fewer Useless Tests

Patient Associations and Scientific Societies Hope for the Recognition of Chronic Thyroid Diseases

Reduction of Healthcare Expenditure through Better Planning of Clinical Controls of Chronic Thyroid Diseases

In Italy there are more than 6 million people who suffer from thyroid diseases. The International Thyroid Awareness Week (ITAW) is an opportunity to talk about the diseases that affect this gland, the importance of a correct diagnosis and appropriate checks. This year as well, the ITAW will be celebrated starting from May 20th and ending on May 25th, on the occasion of World Thyroid Day. "Chronic thyroid diseases: more information, fewer useless tests" is intended to be an invitation, addressed to the entire population, to have an active role in obtaining information, from qualified sources, on health issues and that information is considered part of the recommended life as well as good nutrition and exercise.

Patient organizations and the scientific community ask that the World Health Organization recognize thyroid diseases as NON-communicable diseases which, by definition of the WHO itself, are chronic, long-term pathologies that derive from a combination of genetic factors, environmental and behavioral, thus differentiating itself from contagious infectious diseases, transmissible from one person to another, which cause epidemics. Non-communicable diseases are the main cause of death and disability in the world: cardiovascular diseases, cancer, chronic respiratory diseases, diabetes and even obesity belong in this category. The main interest in having thyroid diseases recognized among chronic diseases lies in the fact that biomedical research in this sector requires substantial funding; recognizing thyroid diseases as chronic diseases would allow access to greater funding for new studies whose results would benefit the population affected by these pathologies.

Antonella Olivieri, (Italian National Institute of Health, Department of Cardiovascular, Endocrine-Metabolic and Aging Diseases) states that it is very important to "do prevention through prophylaxis with iodized salt: nodular thyroid pathology is in fact strongly conditioned by iodine deficiency. Although in Italy, thanks to the campaign on the use of iodized salt which began in 2005, iodine nutrition has improved greatly, the population must continue to be sensitized to using little salt and only iodized starting from pediatric age, in order to significantly counteract the formation of "goiter" and thyroid nodules".

Anna Maria Biancifiori

It can be stated that the prevention of thyroid pathologies occurs both through an adequate intake of iodine in the diet and through real prevention checks but only for people at risk such as individuals over the age of 50, individuals with confirmed family history for thyroid diseases and, among these in particular, women planning a pregnancy and, finally, monitoring the thyroid function of individuals subjected to the intake of certain drugs with a high iodine content such as, for example, amiodarone.

"We are committed to bringing and simplifying, through all our initiatives in the area, adequate and correct information that we believe can help the patient to "live" with these chronic pathologies. This possible recognition among chronic Non-Communicable Diseases will bring both a clinical and economic benefit to these patients", explains Anna Maria Biancifiori, President of CAPE.

Helping Portuguese Find the Missing Piece of the Puzzle

When you don't feel well, when symptoms persist for no apparent reason, your health becomes a jigsaw puzzle and the search for the missing piece begins. Your thyroid gland may well be the answer to that puzzle! This was the starting point for another International Thyroid Awareness Week, which this year (2024) took the Portuguese Thyroid Diseases Association (ADTI), together with the Portuguese Society of Endocrinology and Metabolism and Merck, to the streets for raising awareness and inform the population.

In Portugal, it is estimated that 7.4% of the population has a thyroid disorder, from which the large majority are unaware that they are living with the problem. Raising awareness and helping the Portuguese identify the missing piece of their health puzzle was the main objective of this year's initiative, which took place on May 27th at CascaiShopping, one of the country's largest shopping centers. The event brought together hundreds of people, including public figures, who also posted about the issue on their social networks.

In addition to the TSH test, which identified people at risk of hypothyroidism, these screenings. made with health professionals supervised by endocrinologists, provided information on the signs and symptoms of the disease, helping to dispel doubts, raise awareness and improve health literacy.

It was a week that also increased the sharing on social networks and presence in a variety of media, from TV programs to the written press, enabling us to get our message out to more than 2.7 million people (circa 25% of the total population).

WWW.ADTI.PT

Thyroid Foundation of Canada

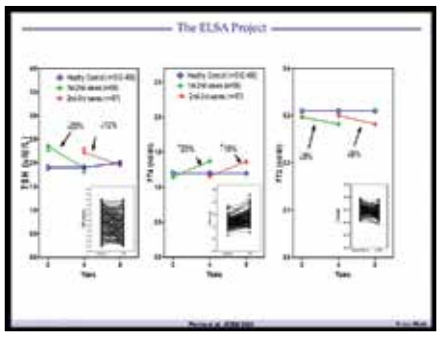
Laz Bouros, President

This past year our efforts for thyroid awareness, patient support, and thyroid research have been very successful. We even invited the medical community to attend two of our webinars. I'd like to review our achievements for 2023-2024.

Awareness/Education initiatives for Hypothyroid Patients with Residual Symptoms

An educational webinar was held on this subject given by Dr. Bianco on April 16th, 2023. We published articles in the Thyrobulletin and the Thyroid Federation International (TFI) newsletter.

Dr. Antonio Bianco



Awareness initiatives for Combination Therapy with the Canadian Medical Community

We promoted the TFC webinar recording of Dr. Bianco with the Canadian Society of Endocrinology and Metabolism (CSEM). We sent a request for the development of guidelines for combination therapy in hypothyroid patients to the CSEM in November 2023. We participated in a CSEM project representing the patient's perspective for the development of a consensus statement on the "Follow-Up Care for Low Recurrence Risk Thyroid Cancer Patients in Canada".

Educational/Awareness Webinars

We provided a total of four educational webinars over the winter/spring. In November, we held a Thyroid Cancer Patient Panel with Dr. Sana Ghaznavi. In March, we held the Ultrasound-Guided Radiofrequency Ablation of Thyroid Nodules (medical version) webinar with Dr. Jesse Pasternak. On May 5th, we've held a webinar on Rethinking Hypothyroidism (medical Version) with Dr. Antonio Bianco. A fourth webinar on Mental Health and Thyroid Disease with Dr. Jack Wall was held on May 26th.

Thyroid Foundation of Canada
La Fondation canadienne de la Thyroïde

TFC Medical Advisors

We are creating a list of TFC Medical Advisors who specialize in areas such as thyroid cancer, thyroid surgery, combination therapy and thyroid eye disease. We reached out to our guest physicians who helped us update our TFC Health Guides. These have been posted on our website.

Raised Funds to Support TFC's Work

We raised sufficient funds to support our work from pharmaceutical organizations, our Light a Tree for Thyroid campaign, memberships, individual donations, and bequests. We finished the year with a small surplus.

Migration of TFC Website to a More Secure Platform

We looked into migrating our website to a more secure platform such as wix.com, that would lower our operating and support costs. We reached out to several consulting firms, met with one consulting firm in Montreal, received an initial estimate to migrate from WordPress to Wix.com platform.

In the meantime, our current website seems to have stabilized and we have not experienced any technical failures. So, we may postpone the migration to a new platform for a later time.

(continued on page 33)

Thyroid Foundation of Canada *(continued from page 32)*

Annual Research Grant for Thyroid Research

As described in our fall Thyrobulletin, the 2023 TFC Research Grant of $50,000 was awarded to Dr. Sana Ghaznavi. Dr. Ghaznavi's research project is entitled "Exploring limitations in the current standard of care for thyroid hormone replacement therapy in thyroid cancer survivors".

Thyroid Information on our TFC website, Social Media & Publish Thyrobulletin

We provided updates on thyroid news items monthly, improved TFC's reach to thyroid patients through social media, updated educational webinars, patient guides information and other events, updated research articles, and published two issues of the Thyrobulletin. We delivered a very successful thyroid overview presentation to SK Seniors Centre Without Walls organization in Jan. 2024.

Moral Support for Thyroid Patients

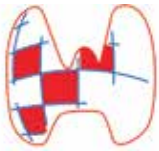
We continued to support thyroid patients through our toll-free 1–800-line, email, and social media. We also improved the patient support process and developed an online integrated enquiry log.

For 2024-2025, we will continue to work on activities we established last year.

We look forward to an exciting and productive year!

Croatian Association for Thyroid Disease in 2023 – 2024

Roko Granić and Marko Kobeščak



The Croatian Association for Thyroid Disease (CATD) has this year reached it`s adulthood celebrating it's 18th birthday. From it`s foundation in 2006, during the first Croatian symposium on thyroid cancer that took place in Split, it has outgrown its childhood ailments: lack of members, financial difficulties, not being recognized and supported by major state and health authorities, to where it is now. CATD is now one of the only several health oriented associations in Croatia that receives full recognition and social visibility not only in the capital of Zagreb but also throughout Croatia and even the regions. From early on, CATD has been patient oriented but with the strong support and council of medical authorities such as the Croatian Thyroid Society, Croatian Medical Chamber; some of their distinguished members, university professors, academics are also members of CATD's Medical Advisory Council (MAC) that helps with questions concerning new methods and medications in thyroidology. In recent years, mostly due to the influence of social media, thyroid patients have been faced with a flood of misinformation and false statements. That is where MAC has played a substantial role in governing CATD towards evidence based sources of information.

During the last year, i.e. from the previous edition of Thyroworld, CATD has hosted and taken part in more than 20 events; public health and cultural manifestations, sport events, held lectures and creative workshops in its headquarters in Zagreb as well as in its affiliates in Slavonski Brod, Križevci, Samobor, Velika Gorica and Umag. With the cooperation and great help from the Croatian Anti-cancer League, CATD is in the process of reaching the regions of Croatia where it has not been represented until now.

Celebrating May 25 - World Thyroid Day in Zagreb.

A special date in every thyroid association`s calendar and the most festive event, is the celebration of May 25th World Thyroid Day that in Croatia traditionally takes place in the center of Zagreb and this year also in Slavonski Brod. CATD members offer pink peonies (the official flower of our Association) to all who visit our stand as well as artistic objects that were handmade during creative workshops.

(continued on page 36)

Croatian Association *(continued from page 35)*

Public health manifestations during the last year that CATD took part in include: "Walking for thyroid awareness" in January, "Christamas/New Year's wishing lights" in Slavonski Brod, "European 112 Day" in association with the civil defence in February. Our creativity was displayed and well noticed several times on Q'Art (quarter art) events in Zagreb when quarters of the city are revitalized with NGO and artisitc public displays.

Hollyday Lights of Wishes, CATD Slavonski Brod.

Croatia is one of the countries with the highest incidence of thyroid cancer in Europe, therefore in January (International thyroid cancer awarenes month) CATD organized a meeting with lectures open to the public where two thyroidologists, surgeon Dr. Gršić and a nuclear medicine specialist Dr. Granić, talked about thyroid nodules, thyroid cancer and thyroid surgery.

With the coming of spring and nice weather in May and June of 2024 CATD was out and about, participating in several sporting events that promote healthy life style which in fact help in maintaining hormone balance and thyroid health. In May, the president of the Association, Verica Mešić, once again walked 60 km from Zagreb to Petrinja – the earthquake ravaged town in Banovina county south of Zagreb – raising funds for an ultrasound machine that is esential for thyroid diagnostics. In June the traditional CATD's

Blue Butterfly Annual CATD race in Zagreb's Maksimir park.

"Blue butterfly race" was held in Zagreb`s Maksimir park with participants coming from all over Croatia to give support to our members that endured the race even under the scorching afternoon sun. After the race there was plenty of time and energy left to socialize and refresh in a beautiful forest ambiance.

The Croatian Association for Thyroid disease has had a very sucessful and eventful year, its membership growing in numbers and affiliate associations spreading, thanks mostly to the volunteers that donate their free time and energy helping patients suffering from thyroid diseases. As one of our volunteers rightfully said: ""One that gives with an open heart, receives back threefold!".

Lecture organized by Croatian Association for Thyroid disease.

Stofskifteforeningen
The Danish Thyroid Association

About Us

The Board of the Danish Thyroid Association, from top left: Julie Davey Dalsgaard Lund (chair), Helene Kremmer Andersen, Cecilie Kaltoft, Bente Julie Lassere, Charlotte Fnug Munksgaard, Louise Roland, Iben Nygaard Mikkelen, Tine Stampe (chief secretary). Not pictured: Mette Rasmussen, Tine Klitgaard Woer (employee).

The Danish Thyroid Association is a non-profit organisation for all thyroid patients and their relatives. The organisation was founded in 1997 and is driven by a volunteer board consisting of nine members, supported by two full-time employees. By the end of June, 2024, we had just over 3,000 members.

For a Better Life

Our main focus is to ensure that all patients can live their best life with their thyroid disease. This requires awareness, knowledge, and support.

Awareness

We believe that by raising awareness of thyroid diseases, we can contribute to a better quality of life for more patients, among other things, through earlier and better diagnoses.

Knowledge

We believe that some challenges for thyroid patients can be solved by being well-informed, which is why we collaborate with healthcare professionals, nutritionists, social workers, and others who can have an impact on the quality of life for thyroid patients.

Support

We believe that there is strength in numbers, which is why we focus on cultivating communites for our members, to share experiences and support each other when life gets tough.

Highlights of 2023-2024

A new platform for patients with hypothyroidism

In January 2024, we launched our new digital platform, mitstofskifte.dk, which is a universe of support, communities and knowledge for those who suffer from hypothyroidism. The site is also useful for caregivers and professionals. The platform contains:

- Videos with patient stories
- Podcasts and articles with experts
- Exercises and support to understand your disease
- Explainers to simplify the complicated topics

Within the first six months of launching, the site has reached 24,000 unqiue visitors, which adds up to 18% of the expected number of thyroid patients in Denmark.

Coffee Meetings

In 2024, we launched a new initiative to cultivate communites among thyroid patients in Denmark.

We have held coffee meetings in 5 locations around the country, where we invite patients and relatives to come by and meet others who are affected by thyroid diseases in some manner.

These meetings are open to anyone interested, with no requirement to be a member of our association. Though the coffee meetings are initaited by us, the goal is for the participants to continue on their own, something we have already seen at one of our locations, which have held two meetings since, with our only involvement being sharing the information in newsletters and on our social media channels.

What Does The Future Hold?

We have high ambitions and hopes for the future of thyroid patients in Denmark.

Currently, we are applying for funds to expand our digital platform to include all thyroid diseases. While hypothyroidism affects the most people in Denmark, we want to be able to help everyone who is struggling with their thyroid. We hope to launch the extended platform in the beginning of 2026.

We want thyroid diseases to be recognised as one of the major chronic diseases in Denmark. To do this, we are working to create alliances with other patient organisations, prominent endocrinologists, politicians, and healthcare authorities. By expanding our network, we hope to raise more awareness of our association and the lack of care and treatment options for thyroid patients.

THYREOIDEA
LANDSFORENINGEN
FORENINGEN FOR STOFSKIFTEPATIENTER

Thyroid Association of Finland (Kilpirauhasliitto)

VESA ILVESMÄKI, MD, PHD.

About Us

Thyroid Association of Finland (TAF) is a national, public health, patient and lobbying organization. It promotes the awareness, care and research of thyroid disease and parathyroid disorders. Our main focus is to take care and support the physical, psychological and social well-being of those who suffer from thyroid and parathyroid conditions. The organization was founded in 1999, and before that there was a small national patient organization from 1996. TAF is sponsored by the Finnish government according to national laws and regulations, as are other patient organizations in our country. At the end of 2023 we had 9 500 members with 14 local chapters in different counties covering the whole country of Finland.

Administration

TAF has an Annual Meeting, where the members of local chapters meet and elect the national board, which meets once a month. Most of the board meetings are via Teams (beginning in 2020). There are nine members on the board. Each member's term lasts two years. The current President of the board is Ms. Leena Kallionsivu. We also have one doctor-member position on the board, who is an endocrinologist or thyroidologist. The rest are usually thyroid patient representatives.

The office of the TAF is located in Helsinki, the capital of Finland, in a building owned by the Organization for Respiratory Health in Finland. Several other patient organizations are in the same building, too. We have 4 rented office rooms there and availability of meeting rooms. The office is located in central, northern Helsinki with good traffic connections. Our staff consists of nine employees, part of who are part-time workers. The head of the office is our Managing Director, Ms. Mirja Hellstedt, MSci.

Local chapters in different counties of Finland have their own boards, and they are funded by the TAF.

Kilpirauhasliitto

Highlights of Recent Activities and Achievements

Kilpi-magazine

TAF publishes its own magazine, "Kilpi" (kilpirauhanen=thyroid in Finnish), which has 4 issues annually. Each issue includes about 50 pages with medical articles, patient articles with personal experiences of living with thyroid disease. There is also a question-and-answer section, where a group of Finnish thyroidologists answer questions. Kilpi was founded in 2011 and now we are working on the 14th annual volume. Its circulation is about 11,500 copies. TAF members get their magazine included with their annual membership fee. It is also sent to different libraries, universities, hospitals and selected health care professionals. The price for non-members is 50e/year. The editor-in-chief is Ms Mirja Hellstedt, MSci, with an editorial board of five other members. Most of the articles are in Finnish, but part is also in Swedish, so it is possible for people from other Scandinavian countries to read these parts of the magazine.

Internet activities

The TAF homepage is thought to be our second most important service after our Kilpi-magazine. There are over 300,000 visits annually and the visits are increasing. There is important information about thyroid and parathyroid disorders. These include Information for Patient brochures. We have also made video lectures and video shorts about hypothyroidism, hyperthyroidism and various nutritional facts about the thyroid. These have been uploaded to YouTube. Beginning in 2023, we have also published five different podcasts, where a patient first talks about the history of his/her disease, and then a doctor comments on the case. These podcasts can also be found on Spotify by the name Kilpi-podi. We also have our own Facebook and Instagram channels, and these are updated continuously.

(continued on page 39)

Thyroid Association of Finland (Kilpirauhasliitto) *(continued from page 38)*

Patient help

TAF has an information telephone and email services for thyroid patients. These are run by thyroid-orientated specialist nurses two days a week (Tuesday and Wednesday) except in July. We also have a support telephone line for patients every Thursday evening. It is run by voluntary thyroid patients to support the burden carried by thyroid patients. This service was also introduced on Finland's national TV channel in October 2023. We also arranged 12 different chat-meetings throughout the year for hypothyroidism, hyperthyroidism and thyroid cancer. There was a different theme every time. This was very promising, and we hope to continue it in the future.

International Thyroid Awareness Week 25-31 May 2024

During the ITAW week our 14 local chapters had 59 different happenings throughout the country. These included informational meetings, lectures etc. in local hospitals, libraries, shopping malls and pharmacies. The local organizations were quite satisfied with the public responses they got. There were also contacts from national media. Reports from these occasions are going to be published in the Kilpi magazine.

Thyroid Association of Finland's info desk held by staff members.

Info desk by the Vaasa Region Thyroid association.

National Guideline for Hypothyroidism

In November 2023, the first National Guideline for Hypothyroidism was published in Finland. The work began in 2021 and was led by endocrinologist Saara Metso, MD, PhD. The working group consisted of endocrinologists, an oncologist, family physicians, a pharmacologist and a specialist in clinical chemistry. It was made under the guidance of the Finnish Medical Society Duodecim, which has published over 100 practical national guidelines from different fields of medicine during the last 25 years. The Guideline is based on different international guidelines and medical articles and reviews.

Future

In the future we will try to increase the number of our members. This is challenging, because there are over 350,000 thyroid and parathyroid patients in Finland. We also want to develop our internet-based services as the world is becoming more and more digitalized.

Thyroid Ghana Foundation (TGF)

The Thyroid Ghana Foundation (TGF), since its inception on 13th July 2018, has been engaged in awareness of thyroid disorders, supporting thyroid patients, and encouraging thyroid research. The foundation embarks on advocacy programs which aim at addressing several thyroid health related issues at the policy and institutional levels and facilitates closer working relations between departments involved in thyroid disease treatment and research. The foundation is mainly supported by the College of Health Sciences (University of Ghana, Legon) including departments such as Medicine and Therapeutic (Endocrine Unit), Child Health, Obstetrics and Gynecology, and Psychiatry.

We also work closely with the School of Biomedical and Allied Health Sciences such as Nutrition and Dietetics, Medical Laboratory Science, Pathology and Surgery, and Center for Radiography and Nuclear Medicine. The TGF also seeks to engage government agencies such as the Ministry of Health, and Food and Drugs Authority to introduce policies toward promoting thyroid health. More critically, the foundation aims to ensure that most thyroid drugs are covered and supplied under Ghana's National Health Insurance Scheme. The TGF, since its launch, has conducted various programs and campaigns on thyroid awareness in the country and beyond, using mediums such as webinars, health walks and talks, and regular engagements with thyroid patients and the media. The foundation is managed by staff and volunteers who readily avail themselves to support its activities.

Past And Present Activities

The TGF has in place a patient support program which pays regular visits to the Endocrine and Surgical Clinics to educate patients on lifestyle changes needed for managing thyroid conditions. The foundation maintains contact and tracks the progress of thyroid patients from these clinics to enable us to support them throughout their treatment process. We offer voluntary registration for patients to join the Foundation's Patient Support Program and gain invitations to seminars, provide financial support and a 24hr help line for patients who may experience crisis or require urgent information.

Interview with beneficiary of subsidized thyroidectomy

THYROID GHANA FOUNDATION
Promoting thyroid health and patients support....

Other TGF activities:

- secured support from three medical laboratory and imaging companies (Lancet, Metropolis and Scanport) and currently offers discounts on all related blood tests and thyroid scans for members of the foundation. The TGF organizes patient forums regularly, which gives patients the opportunity to seek clarity about their condition.
- in collaboration with the University of Ghana Medical Centre (UGMC), still provides surgeries for thyroid patients at a subsidized fee. So far, 86 surgeries have been done successfully.
- held a meeting with Dr. David Goldenberg of Milton S. Hershey Medical Centre (Penn State Health), aimed at fostering a collaboration between the two parties on Thyroid surgeries.
- held an event in collaboration with Akoma-H Productions themed "Ghana Health Awards and Honours 2023" at Alisa Hotel – North Ridge on 09th September 2023. The event, aimed at organizing awards and raising funds for needy thyroid patients, was chaired by Rev. Prof. P. F. Ayeh-Kumi, Board Chairman of the foundation.

Awards

On the dates of 10th September, 05th October 2023 and 11th November 2023, the president/founder of the TGF, Nana Adwoa Konadu Dsane, received the SHERO award from Ghana Outstanding Women Awards (GOWA), the Gender Mainstreaming Awards, and the Lifetime Achievement Award from the Chartered

At the Ghana Outstanding Women Awards 2024

Gender Mainstreaming Awards

(continued on page 41)

Ghana *(continued from page 40)*

Institute of Leadership. These awards were in recognition of her efforts in promoting thyroid health and support for thyroid patients.

Media Campaigns

The TGF is continuously active within the media space to increase awareness of thyroid, its health and related issues. As part of the annual thyroid week celebration, the foundation was hosted by Joy Prime during the PL show on 11th February 2024, Original TV during their 'Adwene pa' show on 27th May 2024 and Metro TV during their Morning Rush show on 30th May 2024.

Activities and Projects of the National Organizations **Portugal**

Portuguese Thyroid Diseases Association

celeste campinho (president)

The Portuguese Thyroid Diseases Association (ADTI) was founded in 2012 from the urge to support patients and their families. Backing up the interests of thyroid patients and representing them, is the main mission of ADTI, which also supports and clarifies on thyroid dysfunctions, partners with health professionals, and intervenes to assure the interests of these patients.

Many activities have been made over the years, with their highest point at the International Thyroid Week, when, in partnership with other organizations and institutions, we manage to take even further the message about the importance of the thyroid and the need for greater attention to its health.

Webinars, TV interviews, social media presence, partnership with local influencers, surveys, outdoor activities and free of charge screenings supported by renowned endocrinologist doctors are within our scope of activities during the years.

The board members of ADTI, as well as renowned endocrinologist doctors and other specialists work in the association for the cause, i.e., all of them are volunteers.

adti associação das doenças da tiróide

The Thyroid Trust

The Thyroid Trust, a UK registered thyroid charity founded in 2019, is dedicated to providing support and reliable information to the thyroid patient community. Led by patients and in collaboration with medical professionals and researchers, the charity offers a diverse range of online and face-to-face peer support and information events.

The brand identity for The Thyroid Trust represents a diverse, open support circle where everyone is welcome. Our colour scheme reflects our values of openness, learning, transparency, professionalism and caring.

The past year at the charity has been very busy with expert talks from Professor Kristien Boelaert, Antonio Bianco MD, Professor Simon Pearce, Professor Lakdasa Premawardhana, Professor Margaret Rayman and Dr Rebecca Lewis. This was alongside hosting our peer support and other information events. We have also been spearheading a campaign to get thyroid conditions on the women's health strategy, in conjunction with our continued T3 campaign work.

On the run up to this year's International Thyroid Awareness week, we hosted a face-to-face peer support in London with our charity ambassador, Poet and Author Mr Michael Rosen. To raise awareness of this year's ITAW campaign around thyroid disease being an NCD we used the hashtag #thyroidjourney. Michael Rosen very generously gave up his time to be our special guest speaker and shared his own personal journey with Hypothyroidism.

To further highlight our #thyroidjourney awareness campaign, we had patients sharing their experiences of managing chronic thyroid disorders both on the blog and patient stories section of our websites and across our social media platforms. Director of The Thyroid Trust, Louise Sellar, organised a fundraising event on World Thyroid Day. Her physical challenge of walking, cycling, and swimming symbolized the diverse journeys of thyroid patients, emphasizing the resilience and determination of individuals facing thyroid disorders.

Link to her fundraising page can be found here:

https://www.thyroidtrust.org

From left to right The Thyroid Trust trustee's Valerie Dennis, Karen George, charity Ambassador Mr Michael Rosen and Director of The Thyroid Trust Louise Sellar.

Continuing our mission to amplify the voices of thyroid patients, The Thyroid Trust contributes a monthly 'Talk Thyroid' column in the UK online health publication 'Health Triangle'. By fostering dialogue and sharing experiences, the charity aims to combat isolation and provide a supportive network for those affected by thyroid conditions.

For too long thyroid patients' voices have been overlooked resulting in people feeling isolated with their condition. We hope to change that. As our message to thyroid patients is "You are not alone".

www.thyroidtrust.org
Twitter:@ThyroidTrust
Instagram:thyroidtrust
Facebook:The Thyroid Trust
Linkedin: The Thyroid Trust

TFI Board Members — Always Working

Nancy and Beate at the TFI table in Milan.

Roko and Nancy at TFI Stand, ETA, Milan.

Ashok and Linda relaxing in Granada.

Ashok during ETA meeting, Milan.

Nancy on her way to the ETA, Milan

Giulia at AGM, Milan.

Ashok and Peter presenting during AGM.

TFI Member Organizations

AFGHANISTAN
Afghanistan Endocrine Society
www.facebook.com/afghan.endocrine

AUSTRALIA
Australian Thyroid Foundation Ltd.
www.thyroidfoundation.org.au

BANGLADESH
Bangladesh Thyroid Association (BTS)

BELGIUM
Leven Zonder Schildklier
www.levenzonderschildklier.be

BULGARIA
VIOM
www.thyroidbg.com

CANADA
Thyroid Foundation of Canada /
La Fondation canadienne de la Thyroïde
www.thyroid.ca

CROATIA
Croatian Association for Thyroid Disease
www.stitnjaca.eu

DENMARK
Stofskifteforeningen
https://stofskifteforeningen.dk/

ECUADOR
Sociedad Ecuatoriana de Endocrinología, Metabolismo, Diabetes y Nutrición
see.org.ec

FINLAND
Suomen Kilpirauhasliitto ry
www.kilpirauhasliitto.fi

FRANCE
Association Vivre sans Thyroïde
www.forum-thyroide.net

GERMANY
Bundesverband Schilddrüsenkrebs – Ohne Schilddrüse leben e.V.
www.sd-krebs.de

Schilddrüsen-Liga Deutschland e.V.
www.schilddruesenliga.de

GHANA
Thyroid Ghana Foundation
www.thyroidghanafoundation.org

GLOBAL
MCT8-AHDS Foundation
www.mct8.info/

GREECE
Hellenic Thyroid Patients Organization
greece@thyroid-fed.org

HONDURAS – AHCAT
Cancer de Tiroides Honduras
www.facebook.com/cancerdetiroideshonduras

INDIA
(Affiliated Member)
South Asian Federation of Endocrine Societies

INDONESIA
Pita Tosca
https://pitatosca.org/

ITALY
CAPE –Comitato delle Associazioni dei Pazienti Endocrini
https://capeitalia.com/

KENYA
Thyroid Disease Awareness Kenya Foundation
www.facebook.com/thyroiddiseaseawarenesskenya

MEXICO
AMeCAT A.C. Asociacion de Pacientes Cancer de Tiroides Mexico
www.amecatmexico.org

NEPAL
Thyroid Foundation of Nepal
nepal@thyroid-fed.org

THE NETHERLANDS
Schildklier Organisaties Nederland
www.schildklier.nl

NIGERIA
Goldheart Thyroid Awareness Foundation
www.goldheartthyroid.com

Thyroidism Awareness and Support Initiative
www.tasinigeria.org

NORWAY
Stoffskifteforbundet
www.stoffskifte.org

PAKISTAN
Thyroid Support Facility of Pakistan
thyroid.pakistan@gmail.com

THE PHILIPPINES
(Affiliated Member)
Philippine Thyroid Association
philippines@thyroid-fed.org

PORTUGAL
Associação das Doenças da Tiróide
www.adti.pt

SERBIA
Inner Wings, Krila u nama
www.krilaunama.org.rs

SOUTH KOREA
Korea Thyroid Association (KTA)
south_korea@thyroid-fed.org

SPAIN
Asociación Española de Cáncer de Tiroides
www.aecat.net

SWEDEN
Sköldkörtelförbundet
www.skoldkortelforbundet.se

UNITED KINGDOM
The Thyroid Trust
www.ThyroidTrust.org

UNITED STATES OF AMERICA
Graves' Disease & Thyroid Foundation
www.gdatf.org

Thyroid Federation International