



2025 marks the 30th anniversary of Thyroid Federation International (TFI), an umbrella organization for thyroid patients worldwide.



TFI is celebrating its
30th anniversary!

Message from
the Editors
From the Board

Tribute
Conferences and
Congresses

News from the
Thyroid Field

TFI
Projects

International
Thyroid
Awareness Week

National
Organizations

Celebrating
30 years of TFI

TFI Member
Organizations

We continue to work with dedication for the benefit of thyroid patients worldwide!

Thyroid Federation International

Established in September 1995 in Toronto, Canada

Founder

Diana Meltzer Abramsky, CM BA (Canada) 1915-2000

Mentor & First President

Dr. Lawrence C Wood (USA)



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Message from the Editors

We welcome you to the 2025 edition of our ThyroWorld newsletter. To celebrate TFI's 30th anniversary, we decided to switch to a new, modern layout of the frontpage!

Thyroid Federation International celebrated its 25th anniversary in 2020 (during the pandemic – so we met only online that year!) We are very proud to be able to celebrate our 30th anniversary together this year, in beautiful Rio de Janeiro! From 6 founding members when the organization was created in Toronto, back in 1995, our federation has now grown to more than 40 member organizations in all parts of the world. TFI has been present at the International Thyroid Congress since 2000 in Kyoto, Japan, then in Buenos Aires, Argentina, in 2005, in Paris, France, in 2010, and in Orlando, Florida, in 2015.

Please come and visit our booth in the exhibition area, or contact us for more information! 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, as well as affiliated members.

Wishing all delegates an interesting congress!

BEATE BARTÈS, LINDA HENDERSON,
KATHERINE KEEN, ROKO GRANIĆ: EDITORS



Beate Bartès

Linda
Henderson

Roko Granić

Katherine Keen



ThyroWorld

Deadline for the next issue: June 30, 2026

Send all submissions to:

The Editors, ThyroWorld

Thyroid Federation International

Email: tfi@thyroid-federation.org

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President's Message

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

Dear Readers,

It is with great pride and gratitude that I present to you our 30th Anniversary ThyroWorld publication. This publication marks another significant chapter in the journey of Thyroid Federation International, and I'm honored to reflect on the progress we've made together.

This year has been one of resilience, collaboration, and growth. Our work is driven by the unwavering commitment to improving the lives of patients, raising awareness about the challenges they face, and advocating for vital changes in care and support. Collaboration and dialogue with WHO, EU initiatives, IGN, ITC, ATA, ETA, LATS, AOTA, ISE, ITS (Indian Thyroid Society), Arab Thyroid Association, Egypt Thyroid Association, ASOPRS, WSOPRAS, ESE, ESPE, EndoERN, South Asian Obesity Forum, and other organization. As we look back on the milestones we've reached, none of this would have been possible without the dedication and support of our remarkable Thyroid disease community that involves patients, doctors, industry and other stakeholders.

I would like to extend my heartfelt thanks to our TFI members in over 42 countries, who continue to inspire us with their strength, stories, and unwavering hope. To our supporters, to doctors who gave us their precious



Ashok Bhaseen

time, and thyroid advocacy allies, your collaboration has been invaluable in amplifying our mission and advancing our shared goals. We also owe a deep debt of gratitude to our volunteers across the globe, our staff, our TFI Board whose tireless efforts ensure that we remain focused on what matters most – the patients and families we serve.

In the pages that follow, you will read about the key initiatives we've undertaken, the people whose lives we've touched, and the remarkable impact we've achieved. I encourage you to take a moment to celebrate our collective success and to see how your involvement, whether through your time, resources, or expertise has made a lasting difference.

As we look forward to the year ahead, we remain committed to deepening our impact, strengthening our partnerships, and advocating for the needs of our community. Together, we will continue to break barriers, create opportunities for growth, and provide hope where it is most needed.

If you want to help or join us, please contact tfi@thyroid-federation.org and visit us on our YouTube, LinkedIn, Facebook, Instagram and other social media channels.

Thank you for being an essential part of this journey. Your support, your interest in TFI, your involvement and your contributions make all the difference.

Looking forward to meeting you at our TFI booth at ITC 2025 at Rio de Janeiro, Brazil.

ASHOK BHASEEN, M. PHARM, MMS
THYROID FEDERATION INTERNATIONAL



TFI AGM 2024 in Athens, Greece

Once again, our assembly took place as a "hybrid" event, in order to allow members from all around the world either to attend on site or to participate online, without need to travel. The AGM took place on Thursday and Friday, prior to the start of the meeting of the European Thyroid Association. The members presented their organizations and activities, and we also had presentations from the president of the local organizing committee, Pr Leonidas Duntas, and by several pharmaceutical companies. The TFI board presented the yearly activity report, the financial report, the TFI projects and activities, and various votes took place both on-site and online. As every year, it was a great occasion to connect and to discuss with the members of TFI all over the world!

Left to right, standing : Maria Silyanovska, Yvonne Lakwijk, Peter Lakwijk, Teo San Luis, Vasa & Helena Ilvesmäki, Roko Granić
Sitting: Bojana Jedoksic, Anna Bokor, Beate Bartès, Linda Henderson, Ashok Bhaseen, Giulia Giombolini
Standing in front: "flat Nancy", representing board member Nancy Patterson (*absent for health reasons*)

Vale Professor Creswell Eastman AO

Australian Thyroid Foundation Principal Medical Advisor

BEVERLEY GARSIDE OAM – CHIEF EXECUTIVE OFFICER –
AUSTRALIAN THYROID FOUNDATION

It is with a heavy heart I write this tribute.

Professor Creswell Eastman AO Endocrinologist, passed away unexpectedly on Saturday 17th May 2025. Prof has been the Head of the ATF Medical Advisory Board since early 2000 and has provided the organisation with education, support and commitment to ensure the ATF provided the best possible information and services for our members.

Prof was awarded two Australians Order of Australia awards, an AM (Member of the Order of Australia) and an AO (Officer of the Order of Australia) for his life's work and commitment to the prevention of iodine deficiency and thyroid disease.

Prof was a Medical Advisor to Thyroid Federation International, a founding father of the Asia Oceania Thyroid Association AOTA and on many boards in Australia and around the world during his lifetime. He was a world leader in iodine deficiency and thyroid disease.

Prof has always been a supporter of the ATF Executive Committee and members of the ATF. He was always available to speak on our behalf, attend meetings, give in person and video presentations, provide interviews and connect with members who needed guidance through their thyroid journey.

Prof's commitment and life's work focused on improving iodine deficiency outcomes in the Asia Oceania Region, Pacific and in Australia. Prof focused on the importance of iodine supplementation for women contemplating pregnancy, pregnant and breastfeeding.

Knowing that iodine was paramount to ensuring the foetal brain development of future generations reached the IQ they were intended was Prof's greatest mission and his passion.



Pr Creswell Eastman, ATF president Beverley Garside and TFI president Ashok Bhaseen at the AOTA conference 2019 in Sydney, Australia

Professor Eastman's extraordinary achievements have not gone unrecorded:

https://en.wikipedia.org/wiki/Creswell_Eastman

In 2017 Prof was interviewed by Richard Fidler for the Australian ABC Conversation series:

<https://www.abc.net.au/listen/programs/conversations/conversations-cres-eastman-rpt/8219208>

Prof was also just as committed to ensuring patient thyroid health outcomes were not compromised. Ensuring patients received a correct diagnosis and treatment was his priority. He always wanted the best for patients.

I will miss not having Prof at the end of the phone or an email, knowing he was always there when I needed advice. He was my colleague, mentor and a dear friend. There will never be another person like Professor Creswell Eastman, and it's been an honour to know and work with him. Prof will be greatly missed by his family, the ATF, his colleagues and all who knew him.

Conferences and Congresses

In the past 10 months, TFI participated in the following events:



Ashok Bhaseen, TFI President, spoke at the opening ceremony at the **Annual Meeting of the European Thyroid Association**, on September 7, 2024, in Athens, Greece, about the TFI mission as a global network of patient organizations and our work for thyroid patients around the world. TFI also had a booth in the exhibition area.



Peter Lakwijk, Past TFI Treasurer, represented TFI at the **EndoBridge Conference** in Antalya, Turkey (October 17-20, 2024).



Ashok Bhaseen, TFI President, participated at the **American Thyroid Association (ATA) Annual Meeting**, October 30-November 3, 2024, in Chicago, USA. This is the largest Thyroid Congress in the world, bringing together the world of endocrinology and thyroidology and TFI was pleased to be present with a booth.



Beate Bartès, TFI Secretary, and Iruoma Ofortube, TASI Nigeria, attended the **5th Congress of the African Society of Endocrinology, Metabolism and Nutrition (SAEMN)**, October 7-11, 2024, in Abidjan, Ivory Coast. Beate Bartès spoke about TFI's work and objectives, and Iruoma Ofortube highlighted the important needs and challenges of thyroid patients in Africa. TFI also gained a new member association, AMT-CI from Ivory Coast (picture with Adjoua Martine Kassi and Antah Diagola).



Linda Henderson, TFI Vice President, gave an overview of the MotherBabyIodine project at the **3rd WIA International Conference on Iodine in Food Systems and Health** on October 7, 2024, in Baveno, Italy, and highlighted the importance of iodine for health for women of reproductive age.



Giulia Giombolini, TFI Treasurer, gave a presentation on the important work of patient organizations and iodine prophylaxis at the **3rd WIA International Conference on Iodine in Food Systems and Health**, on October 7, 2024, in Baveno, Italy.

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Peter Lakwijk, Past TFI Treasurer, presented on Thyromobile at the **3rd WIA International Conference on Iodine in Food Systems and Health** on October 7, 2024, in Baveno, Italy. He pointed out that Thyromobile is not a van, it is a concept, a global campaign that works to enhance the thyroid healthcare delivery system in vulnerable communities.



Beate Bartès, TFI Secretary, participated at the **European Cancer Organisation (ECO)'s European Cancer Summit**, on November 21, 2024, in Brussels, Belgium, along with 450 delegates, leaders in cancer care, survivorship, and prevention across Europe.

Beate Bartès, Secretary TFI, with Prof. Csaba Dégi, ECO President, at the **ECO's Showcase Event**, November 22, 2024, in Brussels, Belgium, where the smartCARE prototype was presented and tested. TFI is part of the Patient Advisory Committee of ECO, and, together with other organizations, contributed to discussions for the development of the smartCARE mobile app prototype to improve the health and well-being of patients and cancer survivors.



Ashok Bhaseen, TFI President, and Dr. Teofilo San Luis, Jr., Member of the Medical Advisory Board, TFI, attended the **Global Alliance for Patient Access** roundtable meeting on Asia-Pacific Maternal and Infant Health and Thyroid Disease in February, in Singapore. The discussions highlighted the critical role of thyroid health in pregnancy and early childhood.

In the picture: Ashok Bhaseen with Dr. Arora (India), Dr. Teofilo San Luis, Jr. (the Philippines), Dr. Sanjay Kalra (India), Dr. Robin Maksey (Nepal), and Dr. Tjokorda Gde Dalem Pemayun (Indonesia).



Beate Bartès represented TFI with a booth in the "Patient Experience Zone" at the **joint congress of the European Society of Endocrinology ESE and the European Society of Pediatric Endocrinology ESPE**, in Copenhagen, Denmark, 10-13 May 2025.

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Conferences and Congresses *(continued from page 7)*



TFI is a partner of Iodine Coalition Europe. Linda Henderson, Vice President, TFI, and Anna Bokor, Communications Director, TFI, met with the members of the **Coalition: EU salt, EUthyroid2, World Iodine Association, Iodine Global Network, Unilever, Culinaría Europe, and Nestlé**, on February 27, 2025, in Brussels.



Roko Granić, TFI Board Member, attended the **World Society of Ophthalmic Plastic Reconstructive and Aesthetic Surgery Congress (WSOPRAS)** on April 10-12, in Istanbul, Türkiye. Collaborating with professionals in the field of ophthalmology furthers our commitment to enhance the quality of life for TED patients.

In the picture, Roko Granić and Tugba Canturk (AMGEN).



At the breakfast event at the **European Parliament** in Brussels, hosted by MEP Stefan Köhler with the support of Iodine Coalition Europe, on March 25, 2025, Linda Henderson, Vice President TFI, and Anna Bokor, Communications Director, TFI, met with policymakers, iodine nutrition experts, and representatives of the salt, food and iodine industries.



Ashok Bhaseen, President of TFI, presented two sessions at the **Thyro Egypt Conference**, which took place from 24 to 25 April, 2025, in Cairo, Egypt. First, he spoke at the opening ceremony about TFI's mission and its work as a global network of patient organizations, and then, he gave a lecture on the interchangeability issues with levothyroxine.

During the **Thyro Egypt Conference**, on 24-25 April, 2025, in Cairo, Ashok Bhaseen, TFI President, was invited to speak at the press conference where he highlighted that it is crucial to discuss thyroid diseases from patients' perspective and strengthen patient engagement through education.



6th ThyroEgypt, Cairo Conference and TFI Partnership

DR. GHADA KHATEEB AND ASHOK BHASEEN

The 6th ThyroEgypt Conference was held in Cairo, bringing together over 450 participants from Egypt and across the Arab world and beyond. The attendees included approximately 150 endocrinologists, 200 internal medicine specialists, and 100 pharmacists, representing a wide range of universities and institutions.

Objectives

The conference aimed to enhance awareness, knowledge, and collaboration in the field of thyroid diseases and related endocrine disorders. It served as a platform for exchanging recent scientific updates and addressing clinical challenges in the region.

International Participation

We were honored by the participation of Dr. Nasser Al-Juhani, President of the Arab Thyroid Association, and Dr. Hani Mubarak, President of the Hadramout Diabetes Association. The conference also welcomed physicians from Palestine, Iraq, Libya, Sudan, and international speakers from outside the Arab region, including Prof. Susan Mandel from the University of Pennsylvania and Prof. Irina Bancos from the United States.

Key Scientific Topics

- Thyroid nodules and thyroid cancer: prevalence, diagnosis, and management.
- Thyroid disorders and women's health.
- Impact of thyroid disorders on short stature and obesity in children.
- A dedicated session on Thyroid Eye Disease.
- Extensive coverage of parathyroid disorders.
- Sessions on adrenal and pituitary disorders.
- Multiple discussions on diabetes and its endocrinological interplay
- A highly engaging lecture on interchangeability issues with levothyroxine, presented by Prof. Ashok Bhaseen, President of TFI, which was very well received by the audience.

Workshops

- A hands-on workshop on thyroid ultrasound.
- A practical session on diabetes technology: from basics to clinical practice.

Key Takeaways

Speakers emphasized the importance of early and accurate diagnosis of thyroid cancer and nodules, personalized approaches in managing endocrine diseases in women and children, and the need for increased awareness of thyroid eye disease. The sessions on parathyroid and adrenal disorders provided valuable clinical insights.

Key Challenges Discussed

- Variability in access to diagnostic tools and medications across regions.
- Need for harmonized clinical guidelines.
- The rising prevalence of thyroid-related disorders among women and children in the region.

TFI Collaboration and Stakeholder Engagement

The partnership with TFI was instrumental in enriching the scientific value and expanding the global reach of the conference. We also engaged with regional associations, academic bodies, and healthcare providers to strengthen networks and share best practices.

Conclusion

The 6th ThyroEgypt Conference was a significant milestone in uniting the endocrine community across borders. We are deeply grateful for the support of TFI

and look forward to future collaborations aimed at improving thyroid health awareness and care on a global scale.



We thank our Sponsors and Supporters



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, Lynda Wegner who diligently took care of the layout and Anna Bokor, who designed the new cover page and added content.

Upcoming Events

To view the most up-to-date information, visit:
<https://www.thyroid-federation.org/events/>

World Congress on Thyroid Cancer (WCTC)
July 9-12, 2025

Boston, USA

4th African Days of Clinical Endocrinology
Adrien Lokou (JAECL), July 17-18, 2025

Abidjan, Ivory Coast

Annual meeting of the American Thyroid Association (ATA), September 10-14, 2025

Scottsdale, Arizona

Fall Symposium of the American Society of Ophthalmic Plastic and Reconstructive Surgery (ASOPRS), October 16-17, 2025

Orlando, Florida

Endobridge, October 23-26, 2025

Antalya, Turkey

European Thyroid Association Annual Meeting (ETA), September 5-8, 2026

Porto, Portugal

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 Hypoparathyroidism Awareness Day



July

Graves' and TED Awareness Month



September

Thyroid Cancer Awareness Month



October 8

MCT8 Awareness Day



October 21

World Iodine Deficiency Day



Graves' Disease: Unmet Need and the Promise of Clinical Research

In this Q&A, Mark A. Lupo, MD, founder and medical director of the Thyroid & Endocrine Center of Florida, discusses the current unmet need in Graves' disease and the promise of clinical research in developing therapies that target the underlying autoimmune pathology.



Mark A. Lupo, MD

Can you tell us about Graves' disease and how it affects your patients?

Graves' disease is an autoimmune condition in which harmful immunoglobulin G (IgG) autoantibodies bind to and activate the thyroid-stimulating hormone receptors (TSHR) on the thyroid, causing the thyroid to overproduce thyroid hormones.¹ It is the most common cause of hyperthyroidism in the U.S.² Symptoms are associated with excess thyroid hormone levels, but also with the autoimmune response to TSHR, and can be wide-ranging and unpredictable, impacting an individual's overall quality of life.^{3,4} What may be less well understood is that Graves' disease and Thyroid Eye Disease (TED) are related autoimmune conditions, both mediated by autoantibodies to TSHR – Graves' primarily affects the thyroid gland, but may also present with extrathyroidal manifestations, such as TED.⁵ If uncontrolled, Graves' disease can lead to serious health complications.³

How is Graves' disease currently treated and what do you see as the unmet need?

Current therapies for Graves' disease target the thyroid gland and have remained largely unchanged for over 70 years, and include antithyroid drugs (ATDs), radioactive iodine (RAI), and surgical thyroidectomy.⁶ All of these options cause the thyroid to reduce thyroid hormone production, but none address the underlying autoimmune driver of the disease – harmful IgG autoantibodies.⁷

In treating Graves' disease, we generally start people on ATDs, which block thyroid hormone production. Ideally, patients can wean off these after 12-18 months.⁷ We generally want to see normal thyroid hormone levels and a negative TSHR autoantibody test (TRAb) before we stop the ATDs, which suggests that the autoimmune activity has subsided.

Unfortunately, we find that the treatment experience with Graves' is often variable. While some patients are easy to manage and successfully achieve remission in about 12-18 months, about one-third of my patients aren't optimally treated with ATDs, meaning their thyroid levels aren't predictably controlled. This can be disruptive to their everyday lives. Still other people can't tolerate ATDs due to side effects, or they may have issues taking the medication consistently.

If ATDs fail, or if the person wasn't a good candidate for ATDs in the first place, we are left with definitive options – RAI or surgical thyroidectomy. I personally don't recommend RAI anymore for most patients because of a possible link to solid tumors and the fact that RAI may exacerbate or result in TED.^{7,8} Surgery is the other option, but there are potential complications and not everyone is a candidate. The other challenge is that with both RAI and surgery, you are destroying the thyroid – the innocent victim – and not addressing the underlying autoimmune disease driver. Once you cross this bridge, you can't go back. The patient then becomes dependent on lifelong thyroid hormone replacement therapy;^{7,8} most of my patients don't want to do this, and some people still don't feel well after the procedure.

All this to say, there remains an unmet medical need for those who cannot tolerate or struggle to achieve control with ATDs, and who want to avoid definitive treatment. These people often have severe hyperthyroidism, thyroid eye disease, large goiters and high TRAb levels.^{9,10}

How is the treatment landscape evolving?

We focus so much on the thyroid because we haven't had the tools to strike back at the underlying driver of disease. Treatment options that target the harmful IgG autoantibodies may offer a new potential approach.^{11,12} This includes investigational anti-FcRn therapies with clinical trials underway.

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What would you tell a patient who is struggling to achieve control?

People with Graves' who struggle to achieve disease control should consider speaking with their doctor about ongoing TRAb measurement – an important tool in assessing treatment response¹³ – and the potential to participate in clinical research to evaluate potential new therapies. Clinical trials are critical to moving the science forward in Graves' disease and potentially leading to new options to treat the underlying autoimmune disease in the future.

Learn more about Immunovant's clinical research for Graves' disease, at [Immunovant.com](https://immunovant.com)

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NEWS FROM THE THYROID FIELD

Thyroid Disease in Middle-Aged People

VESA ILVESMÄKI, MD, PHD. SPECIALIST IN ENDOCRINOLOGY AND INTERNAL MEDICINE. BOARD MEMBER OF THE THYROID ASSOCIATION OF FINLAND

This article has been published previously in "Kilpi" No. 3/2024. Kilpi is the magazine of the Thyroid Association of Finland. The article is written for the situation in Finland.



Dr. Vesa Ilvesmäki

Introduction

As we get older, many chronic diseases become more common. This is also true for thyroid diseases. Previously we have looked at thyroid problems in young adults (ThyroWorld 2024). In this article, we take a look at thyroid disease in middle-aged people. By middle age we mean the age group between 40 and 60 years.

Underactive Thyroid (Hypothyroidism)

As in young adults, hypothyroidism is also the most common thyroid disorder in middle-aged people. Hypothyroidism is even more common in the middle-aged. This is due to new cases and also patients whose hypothyroidism began when they were younger as the disease is usually permanent. The most common reason for hypothyroidism is Hashimoto's autoimmune thyroiditis. It is even 10 times more common in women than in men.

Many patients have different residual symptoms, which disturb their daily life even though they are treated properly with L-thyroxine (T4). The most common symptom is fatigue. This has come out during the last ten years in studies investigating patient satisfaction. Residual symptoms may be due to disturbed alteration of T4 to T3 (liothyronin). The normal thyroid gland produces both T4 and T3, but most T3 is produced in peripheral tissues where they are needed. Normal T3 conversion needs the enzyme type 2 deiodinase, but it is estimated that in about 10-15% of people the enzyme is not functioning properly. These patients can be treated with T3 medication in addition to T4. There has been a lot of debate of this topic in the scientific community during the last few years.

Before starting T3 treatment, other possible causes to patients' symptoms must be considered. In middle-age the risk for other chronic disease is greater than in younger patients. Therefore a proper physical examination with basic laboratory tests is needed. Basic blood count, sugar, liver and kidney tests and inflammatory tests (esr, crp) are needed. More specific laboratory tests for different diseases may be considered depending on the patient. These include iron deficiency, celiac disease, D-vitamin and B12-vitamin deficiencies. Menopause and andropause must be considered, too. Undiagnosed sleep apnea is very common and sleep

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polygraphy is important to perform. Also a psychiatric evaluation must be done.

Overactive Thyroid (Hyperthyroidism)

The most common cause of hyperthyroidism in middle-aged is Graves' disease as it is in younger people. Thyroid lab results are typical (low TSH, high T4) and the diagnosis is usually quite easy for the doctor. The diagnosis is confirmed by a TSHRAb antibody test.

As we get older, the incidence of toxic nodular goiter (TNG) increases. Hyperthyroidism develops gradually and more slower than in Graves' disease. At the beginning there is usually only low or undetectable TSH without any symptoms. Symptoms develop gradually. There may be cardiac arrhythmias, e.g. atrial fibrillation, tremor, increased sweating and various psychic symptoms. It is important to take thyroid tests in cardiac patients, because cardiac problems are increasingly common in middle-age and there may be a thyroid disorder at the same time. Both Graves' disease and TNG are at first treated with methimazole/karbimazole, but TNG always needs radioactive iodide treatment or thyroid surgery. Graves' disease may be cured by only medical treatment, which usually last for 12-18 months.

Thyroid Inflammations

Thyroid inflammations (thyroiditis) are found in all age groups, and they are not typical for any specific age. The most common is Hashimoto's autoimmune thyroiditis, which usually causes permanent hypothyroidism. There are usually no local symptoms in the thyroid gland in Hashimoto's. The second most common thyroiditis is subacute thyroiditis (also called de Quervain's thyroiditis). The thyroid gland is very tender and painful in palpation. Inflammatory laboratory tests (esr and crp) are highly elevated. There is usually

hyperthyroidism in the beginning, but it turns to hypothyroidism after 1-2 months. Hypothyroidism is usually not permanent and thyroid function is usually normalized later. De Quervain's is treated with oral corticosteroids in the acute phase.

Thyroid Nodules and Tumors

Thyroid nodules are most often innocent sidefindings. They are found in 50% of people. The prevalence is increased when we get older. The thyroid gland usually stays it's normal size even if there is more than one nodule. This is due to the good iodine situation in Finland. Iodine deficiency and related goiter have diminished in our country since the 1950s. This is due to a salt-iodination program, which was started in 1949 in Finland by prof. Bror-Axel Lamberg. Later cattle food was also iodinated. If a nodule seems malignant in an ultrasound, it should be biopsied. The risk of cancer is 5% in nodules more than 1cm in diameter. Nowadays there are good radiologic criteria to detect malignancies as early as possible.

Thyroid malignancies are found in young people, but incidence increases in middle-age. In men, thyroid cancer becomes more common after 35 years of age and in women, 10 years later. Incidence has increased by 2.6% in women and 4% in men during the last 20 years (Finnish Cancer Registry, 2022). However, at the same time mortality in cancer has decreased. In the year 2022 there were 379 new thyroid cancers in women and 155 in men (the population of Finland is 5.5 million). Among women, thyroid cancer was the 8th most common of all cancers. The prognosis of thyroid cancer is very good in comparison with many other cancers. The 5-year survival rate was 94% in women and 88% in men. In year the year 2022 there were 57 deaths from thyroid cancer in Finland. So it is not totally innocent as often believed.



Person-Centered Thyroid Care

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Thyroid diseases can easily be classified and studied in relatively few domains: hypothyroidism, hyperthyroidism, thyroid nodules and cancers. Armed with effective and efficient drugs, the thyroid care professional feels competent and confident in achieving health in most of the patients under their care. This optimism, however, is not shared by those whom they treat. Persons living with hypothyroidism complain of dissatisfaction with their management, even if their doctors claim that they have achieved euthyroid status. A similar situation is noticed in persons with other thyroid diseases, who experience impaired quality of life.

People living with thyroid disease need information related to self-care and self-management, psychological and social support, and attention to nutritional and overall medical/obstetric health. These aspects are part of thyroid care provision, and cannot be ignored by core thyroidology or endocrinology.

Each person living with thyroid disease is unique. Each individual has their own values, needs and preferences, and expects bespoke styles and strategies of treatment. Each person also has a highly personalized definition of health and well-being.

It is necessary, therefore, to integrate person-centred care in thyroidology practice. Person-centred care is defined as care that is respectful of, and responsive to, the preferences, needs and values of the individual concerned. This has been expounded as responsible person-centred

care. This enjoins the health care professional to take on the responsibility of sharing appropriate information with the person involved, in an easily understandable manner. Identifying, acknowledging and addressing these issues is part of basic thyroid care.

Even from a purely biomedical prism, person-centred care is of utmost importance. Based upon the phase of life, etiology of thyroid disease, presence of comorbid conditions and personal priorities or preferences, thresholds for screening, diagnosis and intervention may vary. The mode of treatment and targets of therapy also depend upon multiple biomedical factors. A novel definition of euthyroidism, which encompasses biochemical, physical, psychological and social wellbeing, helps understand the goalposts of thyroid management, and works towards achieving biochemical, as well as comprehensive clinical euthyroidism.

Patient advocacy, led by Thyroid Federation International (TFI), strives to fill the gaps by communicating the patients' voices and wishes to persons entrusted with their care. This sensitizes health care professionals to listen, to empathize, and to assist in achieving better health. It is these facets of person-centred care, based upon an understanding of the biopsychosocial model that will ensure better health for all. The TFI Newsletter is an apt medium to foster dialogue and discussion amongst all stakeholders, and promote person-centred medicine in thyroidology.

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TFI YouTube Channel

All our webinars & various interviews & videos are available on TFI's YouTube channel: www.youtube.com/@ThyroidFederationInternational

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



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

Thyroid Disease & Artificial Intelligence" on 25 May 2025
<https://youtu.be/6cnZO5QpLGc>



Now available on our YouTube Channel

Important Role of the Patient Community in Medicine Development and Access

In this Q&A, Steve Mahoney, J.D., M.B.A, President & Chief Executive Officer at Viridian Therapeutics, Inc. shares his thoughts on the essential role the patient community has in the development of new medicines.



Steve Mahoney, J.D., M.B.A,
President & Chief Executive Officer

Who is Viridian and what is your connection to thyroid-related conditions?

Viridian is a biotechnology company focused on developing potential medicines for people living with autoimmune and rare diseases. Currently, Viridian is studying multiple potential new medicines in clinical trials for people affected by thyroid eye disease (TED), an autoimmune condition affecting the eyes that most often occurs when the thyroid is overactive.

We know that we cannot do this without working with others, including the patient community. Their perspectives and experiences provide a distinctive view of the barriers to and gaps in treatment, which help ensure their needs and priorities are accurately reflected in the work that we do.

How has Viridian worked with the patient community, and what have you learned from these engagements?

One example of how we do this is our TED Patient Advisory Council, which we started in early 2024. During monthly meetings, we learn from members' experiences and seek their input on a range of topics. For instance, they provided insights on ways to engage with the community and provide education on TED and our newest clinical trials for a potential subcutaneous injected medicine.

In working with this Council, as well as with others in the patient community, we have learned there is more to TED than what you typically read in scientific journals - bulging of the eyes, double vision, loss of vision.

We hear often that these are not the only symptoms people experience, that the impact of each symptom varies by individual, and that TED can be highly disruptive to people's lives. TED impacts the ability to drive, use electronic devices, read, and work. People have shared that they often experience negative feelings about their appearance, which has an adverse effect on their mental health, and their desire to go out into the world and be around others.

Another common sentiment we hear is that there is a huge need for innovative treatment options. Despite recent advancements, current treatments have limitations. They don't address all the symptoms experienced. They can be burdensome, taking time away from family, friends, work, interests, and other responsibilities.

What are other ways the patient community can engage in the development of new medicines?

The importance of working with the patient community has been recognized by many stakeholders. Regulatory agencies like the European Medicines Agency, health technology assessment bodies, payers, and government entities are all engaging with the patient community to help ensure that their assessments and decisions align with the needs and values of the people who will be using these medicines. Community members contribute to these assessments and decisions through surveys and other evidence generation, comment letters, as well as direct engagement by joining advisory committees and speaking at public hearings.

Where can people learn more about how they can get involved?

People can connect with advocacy organizations who are already part of some of these activities, such as Thyroid Federation International, and with groups like the Patient Focused Medicines Development Collaborative that provide advocacy resources and guides. They can also reach out directly to the stakeholders mentioned earlier and ask how they can be part of their engagement activities.

Lastly, if people are interested in learning more about Viridian or connecting with a member of our Patient Advocacy team, please visit:

<https://www.viridiantherapeutics.com/patients/>

Guest Editorial

Thyroid Advocacy: The World Order Needs Change

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ASHOK BHASEEN, PRESIDENT, THYROID FEDERATION INTERNATIONAL, CANADA

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NITIN KAPOOR, DEPT. OF ENDOCRINOLOGY, DIABETES AND METABOLISM, CHRISTIAN MEDICAL COLLEGE, VELLORE, TAMIL NADU, INDIA; NONCOMMUNICABLE DISEASE UNIT, BAKER HEART AND DIABETES INSTITUTE, MELBOURNE, VICTORIA, AUSTRALIA

Change is Around Us

The world that we live in is changing, and changing rapidly. The challenges that we face, as we try to create a sustainable world, are changing as well. These include the disease, dysfunction and disability that humankind deals with, as it seeks to navigate life in an increasingly unhealthy environment. The health professions are cognizant of these dynamics, and constantly evolve in order to ensure healthier outcomes for all. One example of this evolution is the recognition of noncommunicable disease (NCD) as a major public health concern. From stray and scattered reports, published just a few decades ago, NCD now occupies center stage in global health discourse¹.

Non-communicable Disease

The World Health Organization (WHO) advocates a 4×4 framework for NCD². This includes 4 diseases (heart disease, diabetes, cancer, and hypertension), which are fed by 4 risk factors. While this framework offers ease of understanding, and ease of action, it does not represent the entire spectrum of NCD. Various experts have suggested additions and edits to the 4×4 rubric. Oral health, cancer, and chronic obstructive pulmonary disease have been proposed as worthy additions to the NCD list. In recent years, obesity has emerged as a major disease, with significant adverse outcomes. This too, has been suggested as an inclusion in NCD³.

Voices of the Thyroid

One equally important disease, which deserves mention as an NCD, is thyroid disease⁴.

Thyroid disease, in its various forms (hypothyroidism, subclinical hypothyroidism, hyperthyroidism, subclinical hyperthyroidism, thyroid cancer) is a major public health problem across the world. Noncommunicable in etiology, this group of diseases affects different age groups in varying manners. Relatively easy to manage, delayed treatment can result in negative outcomes, which could have been avoided with timely intervention. If undiagnosed during the neonatal period, congenital hypothyroidism leads to lasting intellectual and physical disability. Similarly, thyroid disease can lead to significant physical, psychological, and social morbidity across all ages of life.

It is noteworthy that thyroid disease is common in the younger, productive population, especially women of child-bearing age. This has a direct influence on the nancial health, not only of the individual and family, but also of the society and nation as a whole. Thyroid disease, if left undiagnosed and untreated during pregnancy, may harm the health of the fetus, and the unborn offspring, too. This phenomenon has been termed as transgenerational thyro-karma⁵.

Voices of Change

All these features of thyroid disease suggest that it must be included as an NCD. Efforts at advocacy, led by organizations such as Thyroid Federation International (TFI) and Global Alliance for Patient Access (GAfPA), are ongoing^{6,7}. At a national level, the Indian Association of Patient Groups (IAPG), a part of the International Alliance of Patients Organizations (IAPO), has initiated efforts in this regard.

Discrimination against Thyroid Disease

Thyroid diseases have been termed “children of a lesser gland”⁸. They usually do not cause immediate death or disability. Rather, their insidious onset and progression leads to delayed dysfunction and disability.

(continued on page 17)

Thyroid Advocacy (continued from page 16)

This characteristic, “a slowly ticking timebomb”, prevents the public from recognizing the thyroid’s links with vasculo-metabolic disease and general ill-health. The poor understanding of environmental determinants of thyroid physiology such as endocrine disruptor chemicals and micronutrients, adds to the inertia.

This inertia is seen not only at a micro-, or individual level, but also at a meso- (system) and macro- (health policy) level as well. Overcoming this inertia is one of the aims of a proactive thyroid health policy. Thyroid inertia can be defined as an irrational delay in institution, intensification or maintenance of appropriate screening, diagnosis, preventive measures or therapeutic interventions related to thyroid health. This includes not only clinical facets of care (diagnostics, therapeutics) but also public health aspects of thyroid health (preventive and social health).

Voices of Collaboration

Such inertia is best tackled through teamwork. For successful outcomes, thyroid disease should not be viewed in isolation. Thyroid health is not just an end in itself, it is also a means to better pediatric/adolescent, obstetric/gynecological, medical, psychological, and surgical health. Thyroid health also contributes to overall national development, by reducing health expenditures and improving productivity. Commentators have highlighted the role of maternal euthyroidism in improving the intelligence of the next generation⁹. These aspects of thyroidology suggest limitless opportunities for advocacy of thyroid disease as a NCD.

Thyroid disease should be viewed, and discussed as a multisystemic syndrome³, with links to existing NCD and ongoing global health programs. Advocacy should include all related specialties, including not only endocrinology, pediatric endocrinology, and obstetrics, but also public health and oncology. Patient organizations can play a major role in getting these diverse disciplines together, to speak in one voice.

From Past Laurels to Future Success

These efforts, based upon path breaking research of illustrious scientists, have succeeded in creating programs on salt iodization, newborn screening for congenital hypothyroidism, and universal screening during pregnancy. Enhanced discussion and deliberation has facilitated inclusion of thyroid screening in treatment guidelines on conditions as varied as atrial fibrillation, dyslipidemia, chronic kidney disease, diabetes, depression, and obesity. Multinational efforts, such as

TFI’s Mother Baby Iodine Initiative¹⁰, ensure action on the ground, while maintaining attention towards thyroid health. This momentum needs to be built upon. Including thyroid disease in national, as well as WHO NCD lists, is the next logical step in our efforts to improve thyroid health.

A concerted and continued effort for thyroid advocacy is needed today, more than ever. Avoiding discrimination between diseases, and ensuring inclusivity in NCD planning, is the way. As the world order changes, one goal must be kept constant: the target of optimal health, including optimal thyroid health.

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How Croatia Reached Iodine Sufficiency – A Success Story

TOMISLAV JUKIĆ, ROKO GRANIĆ, GABRIJELA BULJAN, ZVONKO KUSIĆ – DEPARTMENT OF ONCOLOGY AND NUCLEAR MEDICINE, SISTERS OF CHARITY UHC, ZAGREB (ALSO DEPARTMENT OF HEALTH & THYROID DISEASE REFERRAL CENTER)

Modern epidemiological investigations on goiter in Croatia began after the Second World War. At that time, endemic goiter was present in most parts of Croatia, with the prevalence of 50 - 90% and even the presence of cretinism. Iodine Deficiency Disorders (IDD) in Croatia appeared mostly in isolated northern and north-eastern areas, as well as in mountainous regions of the northwest



Cretins were completely dependent on maternal care and were considered a "curse for the family"

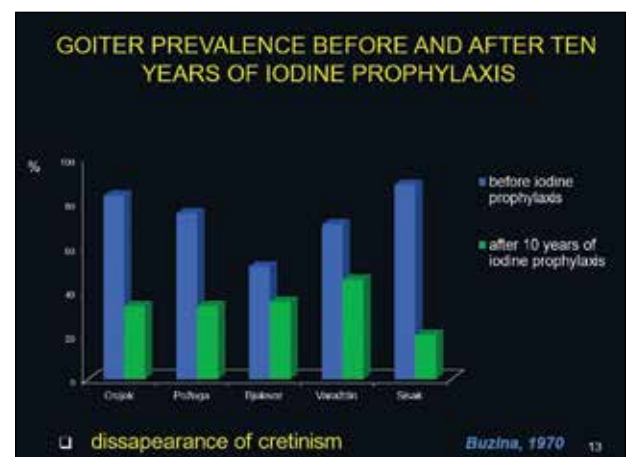
In the early 1950's the incidence of goiter in schoolchildren from continental Croatia ranged between 50 and 90%. In endemic areas, severe iodine deficiency caused cretinism, deaf-mutism, short stature, and low intelligence. The socio-economic consequences of iodine deficiency were significant. High incidence of goiter was also registered in Zagreb, the capital of Croatia with the total prevalence of goiter in schoolchildren reaching almost 50%.



In some villages of north-western Croatia a young girl "without a neck" was not considered beautiful so even angels in the local church were presented with goiters.



In 1953, the first regulation on obligatory salt iodination, requiring 10 mg of potassium iodide per kg of salt was established in former Yugoslavia. At the time, it was one of the most progressive laws on salt iodization in Europe. The program was implemented gradually, over several years, with numerous financial and technical problems. Until 1954, salt was iodized with 5 mg and afterwards with 10 mg of potassium iodide.

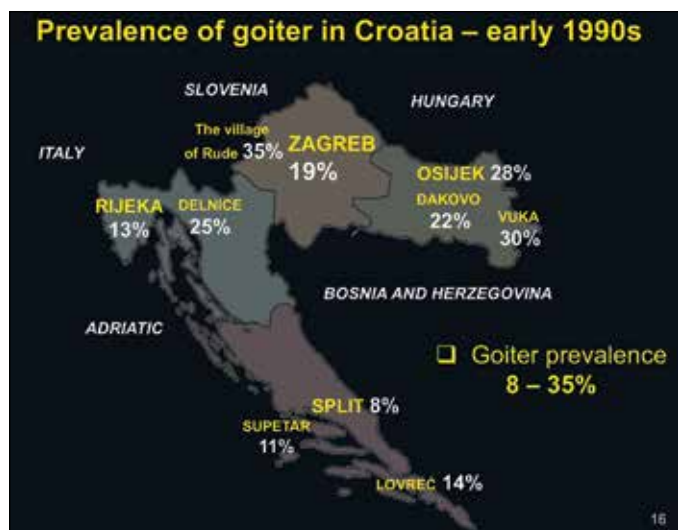


Subsequently, there was a rather long period without any significant research in this area. It was believed that iodine deficiency disorders no longer existed as a public health problem in Croatia. However, at the beginning of 1990s, relatively high prevalence of goiter was recorded in schoolchildren in Croatia. In 1992, "The National Committee for Eradication of Goiter and Control of Iodine Prophylaxis" was founded by the Minister of Health. According to the ICCIDD recommendation, experts of various backgrounds were appointed to the Committee.

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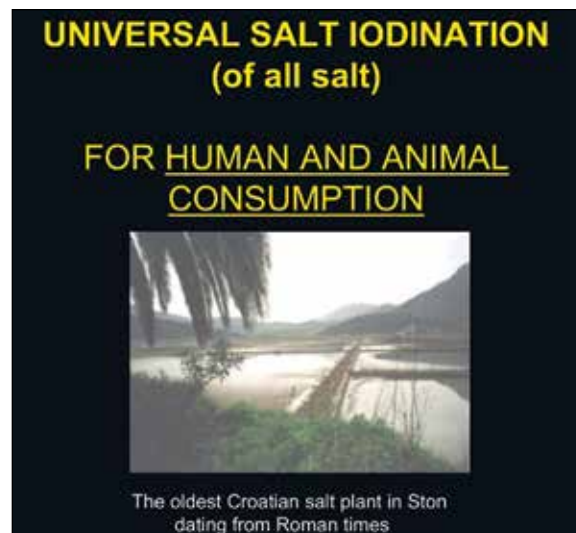
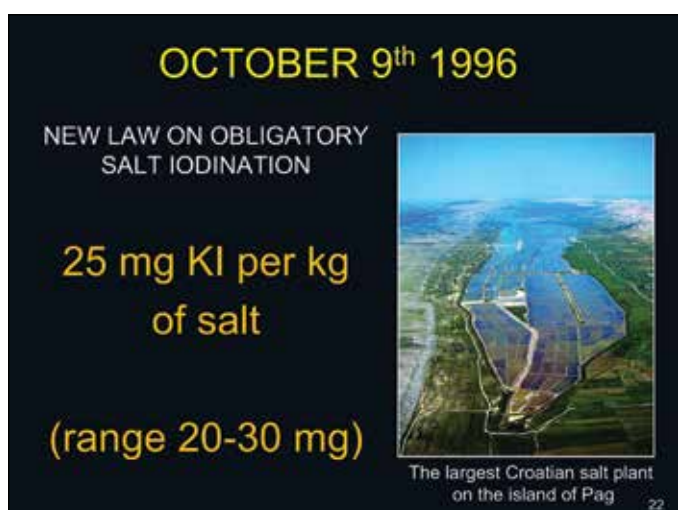
Iodine Sufficiency (continued from page 18)

Epidemiological investigations at the beginning of the 1990s demonstrated that mild-to-moderate iodine deficiency still persisted in Croatia. The total prevalence of goiter among schoolchildren ranged from 8% to 35%.



Medians of UIE (urinary iodine excretion) in schoolchildren aged 7 – 15 years were below recommended value above 100 ug/L, ranging from 30 to 67 ug/L. In continental parts of Croatia (Zagreb and Rude village that was badly affected by IDD), 14-30% of schoolchildren had urinary iodine excretion below 50 ug/L, and 66-83% below 100 ug/L. Median of urinary iodine excretion in Zagreb was 90 ug/L, while median in Rude was 74 ug/L.

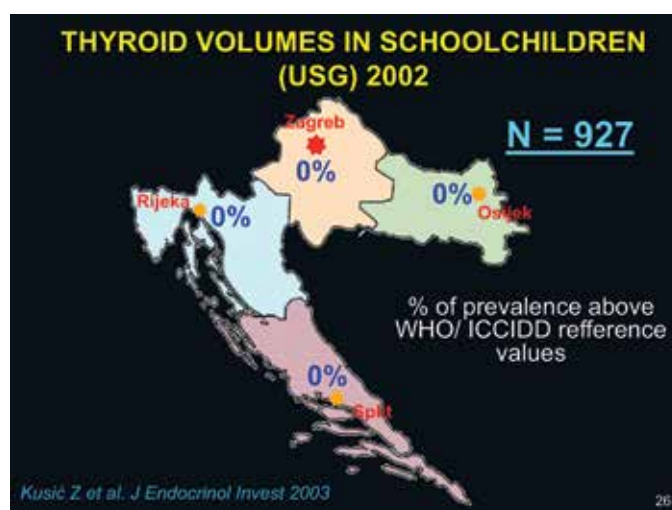
Control of salt produced in the Croatian salt plants in 1995 revealed insufficient levels of KI (potassium iodide). The results of the investigation demonstrated that mild-to-moderate iodine deficiency still persisted in Croatia despite salt iodination with 10 mg KI per kg of salt. The new obligatory regulation requiring 25 mg of KI/kg of salt was proposed. In 1999 measurement of iodine in salt for animal consumption proved an adequate average value of 25 mg KI per kg of salt.



At the same time, a national program of iodine prophylaxis monitoring was established with the main goals including:

- control of iodine in salt at all levels, beginning with producers to end consumers;
- control of IDD with regular epidemiological research of thyroid size, urinary iodine excretion in randomly selected schoolchildren population, and control of neonatal TSH;
- control of iodine-induced hyperthyroidism.

In 2002, Croatia finally reached iodine sufficiency. A total of 927 schoolchildren of both sexes, aged 6-12, were included in the survey. Medians of urinary iodine excretion, detected in all four regions, were within the normal range, according to the ICCIDD criteria. An overall median of 140 µg/L was detected for all target areas. Thyroid volumes of schoolchildren from all four major Croatian regions were, for the first time, within the normal range according to the WHO/ICCIDD reference values. In 2003, the average value of potassium iodine in domestic and imported salt indicated effective iodination as well.



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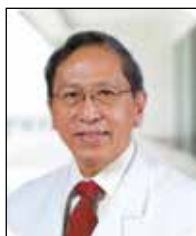
Apart from schoolchildren, measurements of urinary iodine excretion were also performed in adults from the capital of Croatia, Zagreb. Constant improvement of these medians has been noticed. The most recent study shows a sufficiently high iodine uptake in Croatian schoolchildren with the overall median of 24,8 µg/dL of iodine in urine. Thyroid volumes of schoolchildren of both sexes from Zagreb as well as from the worst affected villages were measured by ultrasound in 2009 and proved to be within normal WHO/ICCIDD ranges.

Croatia is a good example of how, through the cooperation between experts, scientists, government, and the general public, a country can cross a difficult path from a high prevalence of iodine deficiency disorders to iodine sufficiency. The Department of Oncology and Nuclear medicine of the Sisters of Charity UHC is the Croatian Ministry of Health Thyroid disease referral center and it serves, in cooperation with UNICEF, as a continuous IDD surveillance center, making sure that the Croatian population stays iodine sufficient in the years to come.

Interview with Dr. Teofilo San Luis Jr.

ROKO GRANIĆ, TFI BOARD MEMBER, NUCLEAR MEDICINE
SPECIALIST, THYROIDOLOGIST, ZAGREB

Dr. Teofilo San Luis Jr (known as “Dr. Theo”) is a medical doctor and nuclear medicine specialist from the Philippines, a pioneer in thyroidology who has been at the forefront of a battle against iodine deficiency disorders in his own country and abroad, inspiring younger generations to selflessly donate their time and efforts to thyroid disease management. Celebrating 30 years of Thyroid Federation International, I had a talk with our “doctor Teo” about his life and professional path as well as his involvement in TFI, helping thyroid patients the world over for many years.



Dr. Teofilo San Luis

RG: Can you tell me how and when your interest in the thyroid gland began, and what was your professional path like regarding thyroid disorders and their management?

TSL: Upon return from post-graduate training in Nuclear Medicine in Germany and having set up my clinic at the University of Santo Tomas Hospital in Manila, the thyroid became the primary focus of my clinical work and research interest. My involvement in the Philippine Thyroid Association (PTA) and the Philippine Society of Nuclear Medicine (PSNM) led me to pursue Thyroidology and promote it in academic and professional circles through lectures, discussion forums and journal publication.

After 2007, when the Philippines hosted the Congress of the Asia-Oceania Thyroid Association (AOTA), I became the Country Representative to the International Council for the Control of Iodine Deficiency Disorders (ICCIDD), which later became known as the Iodine Global Network (IGN). At about the same time, I got elected as AOTA Council Member for the Philippines. In these capacities, I touched base with official Philippine government agencies dealing specially with the health

and nutritional status, particularly of school-age children (SAC) and Women of Reproductive Age (WRA), as shown in surveys revealing alarming results.

I soon realized that much was needed to be done.

In 2015, I was elected AOTA Secretary-General (and later its Vice President in 2020), where concerns for more thyroidal educational initiatives for patients were felt, aside from the usual clinical talks to physicians and other health professionals. Patient education through whatever means is greatly needed and to be enhanced.

RG: Iodine deficiency disorders were rampant among the Philippine population for years. Can you tell me how the MotherBabyIodine initiative began the story of “two lumps”?

TSL: TFI’s thrust on the importance of iodine in pregnancy is depicted in this story of the “Woman with Two Lumps...One Above and One Below”, indicating the situation of a woman with thyroid affliction (usually manifested by goiter) who becomes pregnant...with dire consequences on the child in her womb. This was the highlight of the Goiter Awareness Week celebration in the Philippines in 2009 and has been referred to frequently in many assemblies and lay fora. It is to be noted that not many women are even aware of this “two-lump combination”, leading to disaster when the child is born with impairment. And this situation is now seen more and more frequently, especially in cases of teenage pregnancy where the girl attempts to hide her pregnancy until it can no longer be hidden.

In my various talks, I would often refer (rather half-jokingly) to these two lumps as the “One Above...is by Chance while the One Below...is by Choice.”

RG: Following on the “two lumps” initiative how the idea of Thyromobile in the Philippines came about, how was it received by the officials and local population?

(continued on page 21)

Interview with Dr. Teofilo San Luis Jr. (continued from page 20)

TSL: When official Philippine government data showed WRA iodine nutritional status to be suboptimal, with 15 provinces identified as highly prevalent to IDD, I recognized the imperative to do something to correct the situation from my end. Learning from the experience when the Thyromobile in Europe visited the country way back in early 2000, an unofficial “consortium” was made to enhance thyroid health care delivery to these IDD-vulnerable provinces. With the Iodine Global Network (IGN) in the Philippines taking the lead, I started mobilizing the Philippine Thyroid Association (PTA), the Rotary Club of University District Manila (RCUDM), Thyroid Federation International (TFI), Merck Inc, and the Salinas Foods Inc to the task... and, of course, to tap into their resources! Sort of dividing the work: I provide the “labor” they provide the “capital.” And that started the journey entitled: “From the Clinics to the Countryside.”

And off we went visiting these 15 provinces and provided – free of charge – thyroid educational consultation and screening services with biochemical testing of thyroid hormones TSH and FT₄, imaging of the thyroid using portable ultrasound, and quantitative testing of iodine in household salt samples brought in by attendees and participants using WYD technology. Capacity-building for medical professionals and allied health workers was provided through lectures and informatics.

The Local Government Units (LGUs) provided the venue and all other arrangements; nutrition action officers and village healthcare workers took care of registration and notification of targeted population and coordination with various stakeholders; civic organizations and faith-based troops located in the targeted communities provided logistical support (food and refreshments) in the day-long Thyromobile activities which ultimately benefited their respective constituencies; traditional media operating in the area were requested to broadcast the event and for its coverage during and after the activities to achieve maximum impact while social media played an invaluable role in disseminating information to everyone concerned with thyroidal affliction, whether suspected or actually confirmed. A lot of coordination went into these events.

RG: And the results?

TSL: At the end of the Thyromobile Event in each province, hundreds of women (and a few men) had been attended to, with estimates of those having goiter ranging from 40 - 50%. Abnormalities in TSH (elevated/suppressed) comprised about 15%, with normal FT₄ suggesting subclinical thyroid dysfunction. True hyperthyroidism correlating with the symptoms in the checklist made up about 16%, while true hypothyroidism comprised 9%. Based on ultrasound images conducted on those with thyroid nodules, around 80% of the

clinically palpable nodules were solid in character. And regrettably, some 72% of the salt samples failed to meet the desired level of household of 15 - 40mcg/L or parts per million (ppm), indicating much is still needed to improve salt iodization as per the mandate of the Philippine Salt Law enacted way back in 1994.

RG: How did the local population receive your Thyromobile activities?

TSL: Multiple clinical scenarios came to the fore. Each attendee had a story to tell: the mother of a child with congenital hypothyroidism born at home and out of reach for newborn screening program who thus received appropriate treatment; a teenage pregnant girl with hardly any thyroidal symptoms but hiding her pregnancy and was counseled appropriately; an able-bodied man (though not in the targeted sector of the event) but who requested to be seen because of a lump in the neck recently observed which turned out to be malignant subsequently. Thyromobile can be judged to have made a difference in the lives of many in the community.



RG: Dr. Teo, what is your connection with TFI? How and when did you get introduced to it and joined its efforts?

TSL: I have found TFI as a very responsive organization to patients' needs. Ever since I got involved in AOTA in its Manila Congress in 2007 and as a Council Member, I prodded AOTA's leadership make its congresses happen every 2 years and to look favorably to the hosting of subsequent Congresses in Nagoya (2009), Bali in Indonesia (2011), Kochi in India (2013), Busan in Korea (2017) and the ITC hosting in China in 2020 (but was aborted due the pandemic). In each of these Congresses, TFI was there with its booth providing the ThyroWorld magazine and other educational materials to medical participants and patient organizations.

As a member of TFI's Medical Advisory Group, I helped craft the themes of the International Thyroid Awareness Week (ITAW); other initiatives included moves for WHO to include the thyroid as part of the NCD, which is an ongoing process.

(continued on page 22))

Interview with Dr. Teofilo San Luis Jr. (continued from page 21)

RG: What are your current interests? What do you do and how do you spend your time – any private or professional plans?

TSL: Now that the Thyromobile is getting traction and interest in the media and among civic and professional organizations, we have made plans for the next set of 15 provinces to be visited with more rigorous data gathering for landscape analysis and research. These, plus the continuing advocacy to provide more public information on the evil effects of thyroidal affliction on pregnancy have led us to craft the battle cry of “ResQ- the-IQ” of children born to vulnerable women. This will require more concerted efforts together with colleagues in OB-GYN, Pediatrics and allied health professionals as well as like-minded interest groups, and eventually policymakers.

And to “propagate” Thyromobile. I look at Thyromobile not a mere van with assorted equipment for thyroid diagnostics going from one place to another. Thyromobile



is a concept that needs to be adopted by other countries with considerable burdens of thyroidal disease, with goiter manifesting as only the tip of the iceberg. There is much more affliction beneath the iceberg and below the surface of the water, which wreak havoc to the population. The challenge is there for others to tackle.

RG: Could you tell me about the recent award that you have received?

TSL: It is edifying that our initiatives have been acknowledged. Not that we are working for recognition in itself as its end, but to jumpstart efforts towards collaboration. The Philippine College of Physicians (PCP) took notice of our efforts when it conferred its award to me as Distinguished Health Care Advocate of 2022. One thing led to another. The Philippine Medical Association (PMA) and the JCI Senate named me as one of the 10 Outstanding Filipino Physicians in 2024. And in February 2025, the Philippine Federation of Professional Associations (PFPA) conferred a twin Award for Distinction and Award for Excellence in the medical category.

As humble as our Dr. Theo is, how better to end this conversation than with his favorite Latin quote: “*Non nobis, Domine, non nobis. Sed nomine tuo da gloriam!*” (Not unto us, Lord, not unto us. But unto your name be the Glory!).



Dr Theo receiving the “outstanding physician” award in the Philippines

Graves’ Disease and the ELODI-project

ELSBETH VAN WEES MSC

A new study on the influence of nutrition on the course of treatment of Graves’ disease has started from The Netherlands: the ELODI-project. Graves’ disease is an autoimmune disease and the most common cause of hyperthyroidism worldwide; an overactive thyroid gland in which too much thyroid hormone is produced. The consequences are extensive and include excessive sweating, accelerated heart rate, nervousness, sleeping problems, weight loss and frequent bowel movements.



Elsbeth van Wees MSc.

Most patients suffering from this disease require medical care and are under the treatment of a specialist for an extended period of time.

About us

This special research project was initiated by Elsbeth van Wees MSc; clinical epidemiologist and Graves’ patient herself. In 2016, Elsbeth was diagnosed with both Graves’ thyroid disease and Graves’ eye disease. She wondered if she herself could do something about her

lifestyle and diet to support or speed up treatment, but there was no scientific information on that. She then tried different diets herself and began learning

(continued on page 23)

more about nutrition and dietetics. She then pursued a master's degree in clinical epidemiology at the University of Amsterdam because she was eager to scientifically test the information she had gathered. Her master's thesis consisted of a systematic and scoping review with meta-analysis on the influence of nutrition on Graves' disease. From this master's thesis, the ELODI-project was born. Elsbeth designed a RCT that she will now carry out as project leader from the Amsterdam University Medical Center (AUMC) under the supervision of Prof. Dr. Nieuwdorp, internist-endocrinologist and Dr. Hutten, clinical epidemiologist. Several hospitals in the Netherlands will participate in this project. Elsbeth has thus evolved from patient to scientific researcher with experiential expertise.

The project

In this project, new patients with Graves' disease are asked to participate and modify their diet in addition to the standard drug-based treatment they receive from their treating physician. About 230 patients will participate. Patients who participate in this project will be followed for 2 years.

Quality of life

The quality of life of patients with Graves' disease is often greatly reduced, which is why it is so important that more attention and research is done on this subject. First of all for the patients themselves, but also because the consequences of reduced quality of life have repercussions on our society: people drop out more often and remain unable to work for long periods of time. Quality of life has been included as an important research topic in the ELODI-project.

Outcomes

In addition to quality of life, the impact of diet on achieving remission will also be examined; do more patients achieve normal thyroid function at the end of treatment when adding a modified diet? The amount of medication needed by patients during treatment is also examined, whether this changes when a modified diet is used. Other outcomes being examined in this ELODI-study are the effects of the diet on the amount of antibodies patients develop, on the lipid profile (cholesterol, triglycerides) and what the diet does to the gut microbiome.

What do we hope for?

"Of course, we hope that adjusting the diet will make a significant positive contribution to the course of treatment of this disease; that patients with this disease will achieve normal thyroid function more quickly and for a longer period of time. We have strong indications

to believe that this could work. Adding a diet also gives patients back some of their own control; they can influence their own health. We hope that, apart from getting better faster, this also contributes to an improved quality of life and well-being.

With this study, we can not only investigate the direct effects of this diet on this specific thyroid disease, but also gain more scientific knowledge about the effects of diets in general; knowledge that can be used in the future to treat other diseases."



Received donations

Because there is little to no government funding available for thyroid diseases, this project relies entirely on donations. Elsbeth has received wonderful donations for this project from several funds, allowing the project to get started. However, more funds are needed to fully implement the project in the coming years.

Fundraising and your donation

Therefore, it remains necessary to seek organizations and individuals who wish to support this project financially. Anyone who wants to can make a donation through the AUMC-fundraising page created for this project. If all thyroid patients would make a small donation, we could, with combined efforts, significantly improve the quality of life of patients with Graves' disease! From patients, for patients. Just like Elsbeth is doing with developing this project. You can find the fundraising page via the following link (note; the text is first in Dutch, but then also available in English on the respective site):

<https://www.steunamsterdamumc.nl/project/onderzoek-naar-de-ziekte-van-graves-een-schildklierziekte>

If it is not clear on the website how to donate, but you would still like to make a donation, you can always send an email to the following email address so we can help: elodi@amsterdamumc.nl

If you, as a funder, would like more information on how you could contribute to this special project, you can also contact the researchers at the mail address above. They will then be able to provide you with more information.

We hope to share the various study results with you in the coming years and improve the care of people with Graves' disease.

Thyroid Screening Camp in Kathmandu, Nepal

MAHENDRA RAJ BHUSAL, PROF. DR. MUNI RAJ CHHETRI AND DR. GANDHI SHARMA

Thyroid disorders, especially hypothyroidism, are frequently underdiagnosed in Nepal, largely due to the lack of routine screening programs. Community-based health camps serve as effective mechanisms for early

The Thyroid Screening Camp was organized by Thyroid Foundation of Nepal along with Stupa Community Hospital, Boudha on February 22nd 2025 on the occasion of TFI President Ashok Bhaseen's visit to Nepal. The aim of the camp was to determine the prevalence and demographic distribution of thyroid dysfunction in the screened population. Adults aged above 18 years, who consented to undergo thyroid function testing were screened and blood samples were taken with complete details of each individual who volunteered for the screening. Blood samples were tested for Free T3 (FT3) and Free T4 (FT4)

Normal range was established: 0.4 – 5.0 mIU/L, hypothyroidism: > 5.0 mIU/L & hyperthyroidism: < 0.4 mIU/L. The data were entered into and analyzed using Microsoft Excel and Python. Descriptive statistics (frequency, percentage, mean) were computed, and findings were presented in tables.

Detection and Public Awareness

Results: Among the 222 participants, 71.2% were female and 28.8% were male, with a mean age of 38.0 years. Thyroid function was normal in 84.2% of cases, while 13.5% were diagnosed with hypothyroidism and 0.9% with hyperthyroidism. Thyroid dysfunction was more common among females, accounting for over 83% of all abnormal thyroid cases.

For the full text of this articles go to the link:
<https://www.thyroid-federation.org/media/#world>



Conclusion: The findings highlight a significant burden of undiagnosed thyroid dysfunction, especially among women. Routine community-level screening and targeted awareness interventions are recommended to reduce the hidden morbidity of thyroid diseases in Nepal.

Nepal, where access to regular diagnostic services is uneven, such initiatives offer a practical and cost-effective approach to raise awareness and facilitate early diagnosis.

Despite these limitations, the study underscores the urgent need to integrate thyroid screening into routine community and primary healthcare services. Future programs should incorporate educational components, follow-up mechanisms, and expanded diagnostic panels. Additionally, longitudinal studies are recommended to monitor the progression of thyroid abnormalities and the effectiveness of community-based interventions. We thank Thyroid Federation International for their support to help conduct the screening.

TFI Board Members active around the Globe



Global Alliance for Patient Access, Singapore, February 12, 2025.



Giulia Giombolini, TFI Treasurer, at World Iodine Association meeting in Baveno, Italy. October 2024.

MCT8 Deficiency

Allan-Herndon-Dudley Syndrome (AHDS)

DOMINIKA SCHIEBL, MCT8 RESEARCH E.V

MCT8 deficiency, also known as Allan-Herndon-Dudley syndrome (AHDS), is a rare, X-linked inherited disorder caused by pathogenic variants in the SLC16A2 gene. This gene codes for the transport protein monocarboxylate transporter 8 (MCT8), which is responsible for the intercellular transport of the thyroid hormones thyroxine (T4) and triiodothyronine (T3) and their uptake into the brain. Disruption of this process results in severe neurological developmental delay with axial hypotonia, motor impairments, cognitive deficits and speech disorders. At the same time, excess T3 in peripheral tissue causes thyrotoxicosis with symptoms such as tachycardia, hypermetabolism and failure to thrive. Most affected children are unable to speak, walk, sit or hold their heads up. Parents report pronounced sleep disturbances and feeding problems.

The disease occurs almost exclusively in boys and has a very low prevalence of less than 1 per 1,000,000. The first symptoms usually appear at the age of 2 to 3 months with hypotonia and lack of head control. Diagnosis is often difficult as typical symptoms are delayed, the T3 serum profile is not routinely checked and the disease is not well known. Molecular genetic analysis is required for confirmation.

To date, AHDS cannot be treated causally. Isolated treatment attempts have been made with DITPA, PTU/LT4, LT3, LT4 intrauterine, Phenylbutyrate and Levodopa/Carbidopa. To date, only one therapy with Emcitate (TRIAC) has been approved for the treatment of thyrotoxicosis in MCT8 deficiency, which is why treatment remains symptomatic and based on multidisciplinary care. Initial research results indicate that early diagnosis could be crucial in order to be able to use targeted therapies effectively in the future.

The burden on sufferers and their families is particularly high due to the complex symptoms and severity of the syndrome – many of these challenges are still insufficiently documented and understood. Against this background, there is an increasing focus on patient-centeredness and bidirectional communication channels in order to better identify needs and patient-relevant goals and integrate them into clinical decision-making processes.

DIPL.-INF., M.SC. DOMINIKA SCHIEBL
CHAIRPERSON, PhD-STUDENT
MCT8 RESEARCH E.V.

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TFI Board Members active around the Globe



Beate Bartès, TFI secretary, at the Joint Congress of the European Society of Endocrinology and the European Society for Pediatric Endocrinology in Copenhagen, Denmark, May 2025.



With Prof. Duncan Topliss, Australia at AOTA, Bali, May, 2024.



TFI Communications and Social Media

ANNA BOKOR, COMMUNICATIONS DIRECTOR,
TFI

In the past year, TFI worked to increase visibility across multiple communication channels and promote knowledge in patient education for the benefit of patients all over the world.



TFI website

The TFI team launched the organization's new website (www.thyroid-federation.org), which serves as an essential tool for communicating the organization's goals, impact, important meetings, projects, and collaborations.

TFI Social Media Communications

TFI is actively present on social media platforms to reach people worldwide. We provide evidence-based information through short posts about thyroid diseases for patients and their families. These posts also offer up-to-date information on the latest research in thyroidology for medical professionals and inform stakeholders about the organization's activities and events.

Social media is a powerful tool for patient empowerment and for the support of the thyroid patient community. Thyroid patients get connected to other people with similar health concerns, encourage one another, and often share their experiences in the comments under the posts. The posts process the most recent research articles in a way that they offer easy-to-understand information for patients, and are good reminders for doctors as well.

While Instagram, Facebook, and X target patients and their families, LinkedIn is a platform that aims to reach endocrinologists, thyroidologists, ophthalmologists, healthcare professionals, researchers, nutritionists, and other stakeholders.

In September, on the occasion of Thyroid Cancer Awareness Month, we collected information on what thyroid cancer patients need to know before or after undergoing surgery. With an awareness campaign on thyroid cancer, we worked to bring together the thyroid community in a call to action for coordinated efforts to prevent, diagnose, and enhance treatment and quality of life for those affected by thyroid cancer.

In October, we focused on World MCT8-AHDS Day, World Iodine Deficiency Prevention Day, and World Sight Day. MCT8 deficiency is a very rare genetic disorder with limited therapeutic options. We highlighted that it is important to step up efforts in the

field of research that would lead to new therapies. On World Sight Day, we focused to increase awareness about Thyroid Eye Disease (TED). TED affects more than just vision, it impacts daily life in ways many don't see. It is important that patients receive timely treatment and become advocate for themselves.

January is Thyroid Awareness Month and this year, we dedicated several posts to helping patients understand what is happening when thyroid hormones are out of balance. We designed infographics about the thyroid pathway, the mechanism and function of the thyroid hormones, and illustrated how these hormones affect every organ system in the body.

In February, we focused on two important themes: thyroid autoimmune diseases (Hashimoto's disease and Graves' Disease) as well as rare thyroid diseases. With our campaign on Rare Disease Day, we highlighted the need for new treatments for rare thyroid diseases.

In March and April, we worked to promote the first-ever World Hormone Day. After three successful years of celebrating European Hormone Day, the European Society of Endocrinology (ESE) and the European Hormone and Metabolism Foundation (ESE Foundation) announced the first World Hormone Day, which took place on 24 April. It is within the mission of TFI to put hormones in the spotlight, and with our posts, we worked to increase knowledge and awareness of hormone health.

Several articles focused on the theme of this year's International Thyroid Awareness Week, May 25-31: 'Thyroid and Artificial Intelligence'. There is an increasing interest in applying AI to improve the accuracy of thyroid disease ultrasound diagnosis, monitor disease progression, and help patients with thyroid conditions receive personalized treatment.

Follow us on Instagram, LinkedIn, Facebook, X and YouTube!

TFI in the ECO news

In April, TFI was in the Policy News section of the European Cancer Organisation with an article: 'World Hormone Day 2025: TFI works to raise awareness and push for policy action on hormone health'.

As Ashok Bhaseen, President of TFI, highlighted: 'Hormones are crucial for health. If the endocrine system becomes out of balance, this may lead to the development of Non-Communicable Diseases (NCDs) such as thyroid disorders. World Hormone Day is a

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key moment to reaffirm political support for endocrine health. TFI is committed to working with the EU and stakeholders to support health and research policies that promote endocrine health.’

Many factors can cause the hormone system to be out of balance, including genetics and lifestyle. However, the external environment is increasingly being recognized as a key driver, and endocrine disruption through exposure to chemicals is now widely accepted. More than 1500 chemicals of concern contribute to incidences of endocrine cancer, thyroid disease, infertility, obesity, and diabetes.

World Hormone Day is an excellent opportunity to engage policymakers and encourage them to support health and research policies that promote endocrine health.

Thyroid diseases affect many people. Thyroid patients need to receive adequate information about the disease, regularly monitor their condition, and adjust treatment plans as necessary. Yet, it is equally important that they receive emotional support, and they feel they are listened to. At TFI, we continue to work to amplify thyroid patients’ voices, and empower patients. We believe that when patients are well-informed, engaged, and empowered, this will lead to better compliance and better outcomes in terms of patients’ quality of life.

EUthyroid2 – Raising awareness of the Importance of Iodine Nutrition in Europe and Beyond

ANNA BOKOR, COMMUNICATIONS DIRECTOR, TFI

TFI is a partner of EUthyroid2 consortium and the leader of work package 5 responsible for Communications and Dissemination of Results. EUthyroid2 is a Horizon-Europe health research project that aims to find best-practice models to inform children, adolescents, and young women about the importance of iodine and the risks of iodine deficiency.

The project brings together epidemiologists, endocrinologists, nutritionists, health economists, and communications specialists from a broad range of educational institutions and countries, as well as partners with a global reach, such as the Iodine Global Network and the World Iodine Association.

Iodine deficiency remains a significant public health concern in many countries worldwide, particularly affecting young women of reproductive age. Adolescents and young women are a key target group for interventions as early awareness can reduce the risk of iodine deficiency during future pregnancies.

EUthyroid2 implements community-based trials and interventions in multiple countries in Europe and Asia.

The initial phase was dedicated to the development of a communications plan, brand guidelines, a project website (<https://www.euthyroid2.eu>), a sister project synergy plan, a social media presence (on LinkedIn and X), and the creation of intervention materials.



TFI along with partners in Work Package 5, Work Package 2, and the involvement of regional partners developed educational materials for both ambulatory care and educational study arms.

Interventions in the Ambulatory Care Setting

Ambulatory care setting interventions take place in 5 study regions: Norway, the United Kingdom, Bangladesh, Pakistan, and Poland.

Four core intervention components will be implemented in these regions: an iodine feedback tool, an educational conversation with a healthcare professional, an iodine factsheet, and a video on iodine.

The project results may support regional health authorities in implementing measures to reduce iodine deficiency and associated risks in ambulatory care settings within their healthcare systems.

Interventions in the Educational Setting

The educational setting interventions are conducted in secondary and vocational schools in 6 study regions: the Republic of Cyprus, the United Kingdom, Bangladesh, Pakistan, Slovenia, and Germany, targeting adolescents (13-17 years old).

The main educational material employed in this setting is the ‘The ABC of Iodine,’ with mandatory

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Module A and optional Modules B and C.

Module A consists of a lecture delivered as a traditional in-class instruction, followed by exercises where knowledge will be reviewed.

Module B comprises cooperative learning assignments where students will reinforce their understanding of iodine-related concepts.

Finally, Module C includes a creative task where students will put together a poster for a national campaign highlighting the importance of iodine for

health. Regions have the option to organize local or regional competitions among participating schools, or school leadership can select a local winning poster.

With the help of these interventions, the project will aim to increase knowledge of iodine nutrition among young people and improve their iodine status in order to lay the foundation for their own thyroid and general health and that of their offspring.

For more information, visit the project website:

<https://www.euthyroid2.eu>

Follow EUthyroid2 on: LinkedIn, X

MotherBabyIodine Project

LINDA HENDERSON, TFI VICE-PRESIDENT

The MotherBabyIodine project aims to bring attention to the importance of iodine for health, and the extent and consequences of Iodine Deficiency Disorders (IDD) in pregnant women and women of childbearing age (12-50) that continue to affect both developed economies and countries in development.

Adequate daily iodine intake is essential for women planning to have a child, during pregnancy, and the lactation period. Pregnant women need more iodine intake than other people because of increased maternal thyroid hormone synthesis and iodine transfer to the fetus. Adequate iodine nutrition is crucial for the growth and the brain development of the fetus.

It is important to include iodine-rich foods in the diet, but it is not easy to have sufficient iodine intake from the diet. Universal Salt Iodization (USI) is recommended as the main strategy to eliminate iodine deficiency disorders (IDD), yet, iodized salt is

not available in all countries. Efforts should focus on expanding iodization programs to reach the continuing large number of people who remain unprotected from IDD. Improvements in iodine status will result in major health benefits. The prevention of having children born with a lower IQ due to maternal iodine deficiency would be the main contributor to the overall health impact.

The new MotherBabyIodine brochure is now in Spanish and Italian.

For more information regarding TFI's projects, please contact:

Anna: anna.bokor@thyroid-federation.org

Linda: linda.henderson@thyroid-federation.org



www.motherbabyiodine.com



Bulgaria – VIOM

MARIA SILYANOVSKA, FOUNDER AND
CHAIRPERSON OF THE BOARD OF VIOM

During the International Thyroid Awareness Week 2024, the association VIOM participated in several events:

1. Participation of the association VIOM in a scientific meeting on the topic of rare tumors and primary multiplicity at St. Sofia General Hospital on April 5, 2025.



Presentation of Dr. Marchela Koleva, Founder and Head of the Department of Medical Oncology at St. Sofia General Hospital.

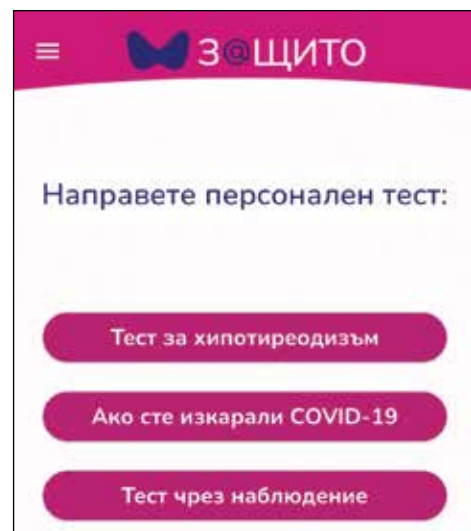


Dr. Marchela Koleva, Prof. Rumen Pandev, Maria Silyanovska Together for a Common Goal: Doctors and Patients United in the Fight Against Rare Tumors.

2. Printed self check brochures for general population.



3. Promotion of ZaShtito – the first algorithm-based mobile application for self-testing and early detection of thyroid disorders in Bulgaria. The app's name is a wordplay meaning 'for the thyroid' in Bulgarian.



Thyroid Foundation of Canada

LAZ BOUROS, PRESIDENT

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



This year, to celebrate our anniversary, we have our very own song about thyroid disease on YouTube to help promote thyroid awareness, see Working on the Thyroid Line and we are starting a new section in our website called "TFC Pioneers!" This section will serve to showcase all those volunteers whose contributions helped to make TFC a success!

Awareness/Education

Last November, we partnered with Celiac Canada to present an educational webinar on Autoimmune Thyroid Disease and Celiac Disease. On April 25th, Donna Miniely gave an excellent thyroid overview presentation to the community senior social group at Queen Square Family Health Team in Brampton, Ontario. We also held a very successful Thyroid Eye Disease Patient Panel webinar with Dr. Kelsey Roelofs on April 27th.



We created a new Hypoparathyroidism Health Guide with a grant from Pendopharm to support a small group of thyroidectomy patients.

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

Advocacy

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

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

Support

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

Research

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

To volunteer, donate or for assistance with a thyroid issue, please contact us at 1-800-267-8822 or by email at <mailto:info@thyroid.ca>.

Wishing all of you a happy and safe summer!



Thyroid Foundation of Canada

La Fondation canadienne de la Thyroïde

Croatian Association for Thyroid Disease

ROKO GRANIĆ (BOARD MEMBER OF THE CROATIAN ASSOCIATION FOR THYROID DISEASE)

Activity report for 2024-2025

The Croatian Association for Thyroid Disease (CATD) has been very active in the past year celebrating its 17th anniversary in 2024. In September and October, CATD presented its activities at the regional tourism and humanitarian manifestation:

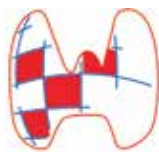


“Fridays in Gorica”, participated in the 5th fundraiser race organized in cooperation with Brodsko-posavska county's League Against Cancer. This year-long cooperation proved

to be extremely valuable in supporting thyroid cancer patients' need for overall social and mental health and wellbeing. In October, a lecture about hyperthyroidism and mental health was held in the earthquake-ravaged city of Petrinja which was very well received.



The creative side of CATD members was demonstrated by enthusiastic interest in a cold porcelain workshop held in CATD headquarters. That was a great opportunity for members and volunteers to socialize as well as to create handmade items to be offered at CATD humanitarian events.



The year ended with a series of lectures about mental help for oncological and thyroid patients held in the CATD headquarters in Zagreb, followed by the celebration of CATD's anniversary, with a classical music concert and a cocktail dinner for all those who helped and supported CATD in any way during the past year.

The Association presented its activities by taking part in a Q'Art project bringing together the local community and NGOs promoting healthy lifestyles. In December, our members participated in the “Zagreb Advent Run 2024” in the center of Zagreb and held a dinner benefit with the International Women's Club Zagreb, a humanitarian organization gathering successful women from different walks of life, raising funds and networking to promote healthy habits and accomplished lifestyles.

2025 kicked off with the presentation of CATD activities during January Thyroid Awareness Month, at the Croatian radio-television programme dedicated to health topics.

“Light of wishes”, a traditional humanitarian event sponsored by CATD's subsidiary in Slavonski Brod, and “League Against Cancer”, was held in February in a picturesque old fort from which many lighted balloons were released into the night sky bearing good wishes for health and prosperity. The money collected by selling balloons was in support of CATD activities.



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In February, another cold porcelain workshop was held in Zagreb, where handmade items were created for Easter, and it was very well attended.



In March, the Croatian Association for Thyroid Disease reached an important milestone by becoming an important stakeholder in the Innothyrogen Horizon Europe Project that deals with predisposing factors and genetic biomarkers for thyroid disease. The CATD's input in the project was as a patient advocacy promoter. The project earned highest grades from the European Union's commission and was awarded significant funds.



A round table was held in March at CATD headquarters in Zagreb on the occasion of International Women's Day with the topic "Women's voice – menopause and thyroid". Several medical experts as well as patients debated how menopause and its hormonal disturbances can affect the thyroid and the overall well-being of women.

The Croatian Association for Thyroid Disease plans, in the next period, to put greater emphasis on reaching the parts of Croatia that are still not covered by its activities, to start its own yearly news bulletin and to continue serving and connecting volunteers, experts, patients' families, and all those involved in thyroid patients' lives.



Pink peonia: CATD official flower celebrating World Thyroid Day, May 25th



May 25 to 31, 2025
**15th International
Thyroid Awareness Week**
www.thyroidweek.org

Thyroid Association of Finland (Kilpirauhasliitto)



VESA ILVESMÄKI, MD, PHD. BOARD MEMBER

About Us

Thyroid Association of Finland (TAF) is a national patient organization. It is also a registered association. TAF promotes awareness, care and support for thyroid diseases and also parathyroid disorders. It was founded in 1999 and in 2024 it was our 25th anniversary. We are led by patients but work closely with medical professionals and researchers. We also have one doctor-member in our national board, who is an endocrinologist or thyroidologist. We have about 10 000 members with 14 local chapters in different counties of Finland. Most of our activities happen locally with these chapters, but we also have many different activities covering the whole country. We have a central office in Helsinki with nine employees. The office is led by a Managing Director (Ms. Mirja Hellstedt, MSci). Our national board meets once a month and is led by our President, Ms. Leena Kallionsivu. Most of our activities are financed by the Finnish government according to our national laws. This kind of support system, which also occurs in other Scandinavian countries, is highly recommended also to other countries. It is the result of long-term political influence over decades. It is very difficult or even impossible to develop and maintain this kind of activity based only or mostly on a voluntary basis.

Kilpi Magazine

Our most important goal is to increase cooperation with health care professionals to improve patient health and well-being. To achieve this, we have many different activities. Our Kilpi magazine is very important to us, and it has 4 issues annually. Each issue includes about 50 pages with expert articles, patient experience articles; local chapters have their own pages, too. Kilpi-magazine was founded in 2011, and now it is in its 14th year. The major topic in 2024 was a 4-article series of thyroid diseases in different age groups from childhood to old age. The circulation of the magazine is 11 500 copies/number.



Patient Information

The most important single site for patient information is our home page (www.kilpirauhasliitto.fi). It has been in active use and there were 376 320 visits during 2024. We have updated and published new versions of our most important patient information booklets last year (Hypothyroidism, Hyperthyroidism and Parathyroid disorders). These can be found in the home page but also printed versions are available.

Patient Help

We have a telephone service for patients to ask questions on two evenings every week (Tuesday and Wednesday, from 5 to 7 pm). We have three professional nurses, who run this service. They can also be contacted by email. During the year, there were 181 telephone calls and 93 emails. A typical phone call lasts about 20 mins. We also had voluntary telephone support by thyroid patients every Thursday from 6 to 9 pm. We have 10 volunteers doing this, and this past year they had 92 calls with patients. The calls lasted between 5-102 minutes.

Projects

The year 2024 was the last of a 3-year project, "Teachers and facts" ("Opet ja opit" in Finnish). The goal of this wide project was to increase the knowledge of thyroid diseases to the general population. The

aim was also to produce material for healthcare professionals and our local chapters to use at their own events. The project included podcasts, videolectures and thyroid guide education. We have produced six different podcasts, which are uploaded to Youtube (hakusana "Kilpi-podi"). Videolectures (about 40-45 min) are also uploaded to Youtube and the topics include hypothyroidism, hyperthyroidism and the effects of thyroid disorders to the heart. We have also made 9 different short videos about thyroid and nutrition. Thyroid guides are voluntary persons, who have been educated to produce and distribute thyroid knowledge to various internet platforms like Facebook, Instagram and Threads. This work


(continued on page 34)

Finland (continued from page 33)

has been very promising and it is continuing on a voluntary basis. We have also produced a Thyroid Quiz, which can be played on our homepage. This includes very basic questions and answers about the thyroid and its disorders. In addition, we have created a database of the most commonly asked questions on our homepage.

Major Events in 2024

We met with our local chapters regularly with coffee meetings 8 times during last year. In August we made a 2-day cruise from Helsinki to Visby (located in the Isle of Gotland, Sweden). There were 85 participants in the cruise. We had lectures during boat trips and in Gotland we spent one day exploring this wonderful island. We also organized 6 different empowerment and rehabilitating courses for thyroid patients during last year. They lasted usually for a weekend with some elongation via internet-meetings. There was also a one-weekend meeting for families who have a child with a thyroid disease.




Kilpirauhasliitto
THYROID ASSOCIATION FINLAND

The Thyroid Association Finland increases the awareness of thyroid and parathyroid diseases, treatment and research, as well as the physical, mental and social well-being of patients with thyroid and parathyroid diseases.

There are 14 local chapters of The Thyroid Association Finland throughout Finland, with 10 000 members altogether.

Local chapters of the
Thyroid Association Finland





Future

A new brand strategy was made during last year. Hypothyroidism was chosen to be the topic, because it is the most common thyroid disease and many people are unsatisfied with their treatment. We are going to put an effort into making contacts with health care providers, professional societies, universities and the medical industry. We will try to increase the effective use of the new national guideline of hypothyroidism, which was published in 2023.

If you are interested to hear more about our organization and its activities, do not hesitate to contact our office!

TFI Board Members active around the Globe



With Dr. Shashank Joshi from India and Dr. Akhira Miyauchi of Japan at AOTA Bali, May, 2024.



Beate Bartès, TFI secretary, at a workshop for Thyroid Eye Disease patients at the AMGEN factory in Munich, Germany, April 2025.

Doctor-patient symposium: Treating thyroid differently

HARALD RIMMELE, DIRECTOR – WWW.SD-KREBS.DE

To celebrate the 25th anniversary of thyroid cancer self-help in Germany, the *Bundesverband Schilddrüsenkrebs - Ohne Schilddrüse leben e.V.* organized a symposium and workshop in Augsburg on 21 September 2024.

Researchers working on thyroid hormone substitution, quality of life and long-term effects of hormone substitution are confronted with countless and sometimes contradictory results from clinical and registry studies. There is often great mistrust among researchers regarding patient preference. The American guideline for the treatment of hypothyroidism, published in 2014, lists a total of 15 key areas that need better research in the future. Among other topics, it calls for better assays to determine thyroid hormone levels in the blood and for better medication. However, not a single one of the research priorities directly addresses quality of life. Patients only appear on this list when it comes to how compliance (following doctors' instructions) when taking thyroid hormones can be improved.

It is indeed a problem that many patients do not notice any change in their quality of life when they forget to take their thyroid hormones, whereas on the other hand, some notice the slightest change in dose and suffer from a variety of different complaints, from concentration problems and fatigue, palpitations and aching muscles to weight gain during substitution. This situation requires a great deal of patience until a new thyroid hormone level is reached.

There is also the problem that **patient preference** often tends towards relatively **low TSH levels**, which are **statistically associated with increased risks in the long term** – regarding osteoporosis, cardiovascular diseases...

For the symposium in Augsburg, the German self-help organization therefore brought together leading thyroid researchers from Germany and patients, in order to formulate their wishes for research.

Researchers from the fields of surgery, endocrinology, nuclear medicine and psycho-oncology presented their research and research questions in input presentations. The researchers then entered a direct dialog with the patients,



whereby different perspectives were taken. How can quality of life be improved, how can quality of life be measured, which comparison groups are useful for research, etc.

In four **input presentations**, the researchers highlighted the research needs in their specialist areas:

Research needs from the perspective of surgery, Prof. Dr. Lorenz, University Hospital Halle

Research needs from the perspective of endocrinology, Prof. Dr. Führer-Sakel, University Hospital Essen

Research needs from the perspective of nuclear medicine, Dr. Eilsberger, University Hospital Marburg/Gießen

Research needs from the perspective of psycho-oncology, Prof. Dr. Singer, Mainz University Hospital

Following the input presentations, the researchers then discussed with patients in **six workshops (research cafés)**:

- Relatives
- Online participants
- Thyroid hormones
- Radioiodine therapy
- Aftercare
- Psycho-oncology

The results of the workshop are available at:
www.sd-krebs.de/25jahre



C.A.P.E. — Endocrine Patients Association Committee, Italy

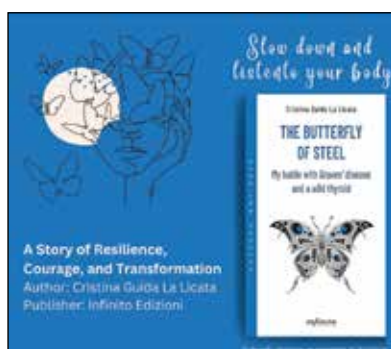
ANNA MARIA BIANCIFIORI, PRESIDENT CAPE ITALY
GIULIA GIOMBOLINI, SECRETARY CAPE ITALY

Some news about our activity:

C.A.P.E. (Committee of Endocrine Patients' Associations) is a committee of Endocrine patients' associations throughout the Italian national territory, with the aim of guaranteeing patients access to all treatments, psychological support, as well as organizing health awareness and prevention events. As of today, associations from various Italian regions include Umbria with La Lumaca Odv, the Marche with Amati. M, Emilia Romagna with Aibat Parma, Puglia with the help group association thyroid (G.A.T.), Campania with Ameir Irpinia, Tuscany with Atta Livorno, Liguria with Ape la Spezia, and Trentino Alto Adige- Veneto with Atta3Veneto, our last new entry.

Here are some activities and projects that our association has delivered this year.

Promotion of a book by Cristina Guida La Licata entitled "The Butterfly of Steel", a Journey of Transformation and Awareness in Thyroid Health. Cristina's journey with Graves' Disease is a powerful testament to resilience, self-discovery, and transformation. Her story is more than a personal narrative, it is a beacon of hope and a call for greater awareness of thyroid diseases, which remain widely underestimated and often overlooked.



She embraced her vulnerability and transformed it into strength, ultimately reshaping her life and career around a new purpose: inspiring and empowering others through awareness and

emotional intelligence. Today, Cristina is a motivational speaker, moderator, and certified emotional intelligence trainer, specializing in personal and professional development. Through her work, she helps individuals unlock their potential, cultivate self-awareness, and build resilience principles deeply rooted in her own experience.

Workshops about Graves' Disease

TED: Therapeutic diagnostic pathway of patients with thyroid orbitopathy.

In a meeting held in Rome, the gaps affecting the diagnosis, treatment and follow-up path of patients with TED were analyzed. The most important unmet needs of this population cluster were identified, and we worked



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together to find unique solutions that could also reflect the growing need for care personalization.

Conferences about thyroid disorders and thyroid cancer, with thyroid specialists and surgeons from Italy and Europe, and patients, a special moment for discussing scientific updates and active listening to patients' needs.

1st Italian Thyroid Cancer Summit - ITCO Report 2025 (ITCO- Italian thyroid cancer observatory).



MANIFESTO 2025

Ten Strategic Lines for Innovation in the Management of Thyroid Cancer in Italy

The drafting of this Manifesto represents the result of a significant joint effort between high-level specialists, scientific societies, and patient associations. The meeting clearly highlighted the importance of real-life studies as a key element for the progress of oncological research, without, however, neglecting the critical issues already known, such as the management of overdiagnosis and, in particular, overtreatment in low-risk thyroid carcinomas.

The multidisciplinary approach continues to confirm itself as a fundamental pillar both in research and in clinical and surgical practice, proving to be the most effective strategy for dealing with highly complex pathologies. A very important element is represented by the integration of digital pathology: the digitalization of anatomical-pathological data would allow the standardization of clinical information, improving diagnostic accuracy and promoting a more integrated management of the patient.



Association des Malades de la Thyroïde (AMT CI), Ivory Coast

The association is one of the newest members of TFI. It was created in 2000 and joined TFI in autumn 2024. At present we have approx. 40 members.

Activities

In October 2024, we participated in the congress of the African Society of Endocrinology, Metabolism and Nutrition in Abidjan, with a booth. In December, participation in the international day for human rights at the Abobo townhall.

20-21 February 2025: participation in the 16th annual congress of the African Society of Pediatric Endocrinology in Abidjan.

26 March 2025: workshop on thyroid, diabetes and hypertension organized by the Pasteur institute.

17 April 2025: participation in the world day against hemophilia.



Beate Bartès, TFI Secretary, and Iruoma Ofortube, TASI Nigeria, attended the **5th Congress of the African Society of Endocrinology, Metabolism and Nutrition (SAEMN)**, October 7-11, 2024, in Abidjan, Ivory Coast. Beate Bartès spoke about TFI's work and objectives, and Iruoma Ofortube highlighted the important needs and challenges of thyroid patients in Africa.



TFI Board Members active around the Globe



At the WHO Geneva Health Forum putting a case for thyroid diseases to have them included as NCD, May 30, 2024.



Nancy Patterson and Beate Bartès at the TFI booth at the ETA meeting in Milano, September 2023.



Thyroid Awareness and Support Initiative (TASI NIGERIA)

IRUOMA OFORTUBE

Thyroid Awareness and Support Initiative (TASI) is the foremost patient-led non-profit organization, legally registered and established in Nigeria since 2017. TASI is dedicated to promoting thyroid health, advocating for thyroid disease awareness, and supporting individuals living with thyroid conditions. Our mission is to empower individuals and communities affected by thyroid diseases by providing education (knowledge), affordable and accessible healthcare, and resources that enhance overall well-being.

We are also committed to advancing research and innovation in thyroid disease management, influencing health policies, and offering emotional support to patients and their families. Our efforts have been made possible through strategic partnerships and collaborations with healthcare experts and relevant stakeholders, alleviating the pain and suffering of thyroid patients across Nigeria and Sub-Saharan Africa.

Milestones and Achievements (2024/2025)

Despite economic challenges in Africa, TASI continues to thrive, pushing forward with its goals to raise awareness and support thyroid patients. In September 2023, TASI, as a Nigerian member of Thyroid Federation International (TFI), attended the TFI Annual General Meeting and the 45th Annual Meeting of the European Thyroid Association in Milan, Italy. This opportunity, made possible by TFI's onsite support, allowed us to network with global thyroid advocates and strengthen our capacity to advance thyroid health advocacy and research in Nigeria and Sub-Saharan Africa. Our President, Amb. Iruoma Ofortube, represented TASI on this global platform.

African Diabetes Congress Participation

TASI's attendance at the African Diabetes Congress was a significant event, with President/Founder Amb. Iruoma Ofortube representing the organization and other African patient organizations, under the platform of TFI.

Thankfully, the trip, fully sponsored by TFI, took place in Abidjan, Ivory Coast from October 7-11. During the congress, Amb. Iruoma introduced other African patient organizations, highlighted progress and challenges, and advocated for thyroid diseases to be recognized as important endocrine disorders and major primary health challenges that require significant attention.

Her advocacy efforts focused on fostering collaborations and partnerships with relevant medical personnel and other stakeholders to improve awareness, treatment, and management of thyroid disease, ultimately enhancing the quality of life for patients; providing quality, affordable, and equitable healthcare for thyroid patients. This initiative aligns with broader goals of addressing diabetes and other Non-Communicable Diseases in Africa, as seen in other continents such as America and Europe.



Iruoma Ofortube, TASI, and Beate Bartès, TFI secretary, at the Congress of the African Society of Endocrinology, Metabolism & Nutrition (SAEMN), Abidjan

Key Activities (2024/2025)

Thyroid Health Awareness and Advocacy

Our intensive awareness campaigns have led to a significant increase in the registration of thyroid patients, and members of our support group, many of whom were previously undiagnosed due to ignorance, societal stigma, or fear of surgery. TASI's helpline receives at least 20 calls daily from patients seeking support—ranging from access to diagnostics and medical specialists to psychosocial, financial, and emotional assistance. Notably, about 70% of these patients require psychosocial and emotional support, prompting us to develop innovative ways to address the mental health challenges associated with thyroid disease.

Beach Outreach for Mental Health Support

Recognizing the overlooked mental health challenges of thyroid patients, TASI organized a Beach Outreach specifically designed to promote stress reduction, nature therapy, social support, and holistic wellness. This initiative created an inclusive space where patients could connect, share experiences, and build a supportive community, reducing feelings of isolation and stigma. Given the success of this program, we plan to expand the initiative to further promote mental health awareness and support within the thyroid community.

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Media Awareness Campaigns

To broaden our reach and educate the public on thyroid health, TASI leverages social media platforms such as Facebook, Instagram, LinkedIn, and YouTube. Collaborations with online print and electronic media have amplified our voice, allowing us to disseminate vital information to both urban and rural communities. Print and electronic media remain powerful tools for reaching a wider audience, ensuring that thyroid awareness is accessible to all.

Medical Missions & Outreaches

TASI extends its outreach efforts to underserved rural communities through medical missions conducted in collaboration with healthcare providers, the Primary Healthcare Board, pharmaceutical companies, and corporate organizations. During this mission, we provide free basic laboratory tests, including thyroid function screenings, while simultaneously conducting community sensitization. Public awareness campaigns are carried out in marketplaces and public spaces, utilizing local languages to drive home critical messages. This initiative has benefited more than 20 communities, particularly during the International Thyroid Awareness Week (ITAW) in May.



Free Surgical Outreach

In addition to awareness and screenings, TASI provides medical and surgical support for affected patients. Every two years, we organize a free surgical outreach, with over 250 beneficiaries receiving either free or subsidized surgeries. Our dedicated medical team plays a crucial role in ensuring that patients receive the necessary care and treatment.

For more information, support, partnership opportunities or collaborations, please contact us at:

tasinigeria@gmail.com

www.tasinigeria.com +2348033348888

Facebook Page: <https://www.facebook.com/p/Thyroid-Awareness-and-support-Initiative-100064525908988/>

Instagram: https://www.instagram.com/thyroid_awarenessnigeria/

X: @fightthyroidism

Adopt-a-Patient Scheme

Due to the overwhelming number of thyroid patients requiring financial assistance, TASI launched the Adopt-a-Patient Scheme. This initiative enables charitable individuals, corporate organizations, and philanthropists to sponsor the treatment and surgeries of underprivileged patients. This program remains a cornerstone of our impact, ensuring that more patients receive the care they need, even in the absence of external grants.



Collaborations & Partnerships

In July 2024, TASI hosted a successful webinar in collaboration with TFI, themed “Improving Global Health Through Thyroid Awareness (Thyromobile)”, with Dr. Teofilo San Luis as the guest speaker. Additionally, TASI partnered with TFI to translate the MotherBabyIodine handbills into Nigerian local languages, further extending the reach of critical thyroid health information.

Commitment to Capacity Building & Growth

In July 2024, TASI hosted a successful webinar in collaboration with TFI, themed “Improving Global Health Through Thyroid Awareness (Thyromobile)”, with Dr. Teofilo San Luis as the guest speaker. Additionally, TASI partnered with TFI to translate the MotherBabyIodine handbills into Nigerian local languages, further extending the reach of critical thyroid health information.

Looking Ahead

With the continued support of our partners, stakeholders, and the community, TASI remains steadfast in its mission to improve the quality of life for individuals living with thyroid disease. We are committed to expanding our programs, strengthening our advocacy efforts, and ensuring that thyroid patients across Nigeria and Sub-Saharan Africa receive the care and support they deserve.



Portuguese Thyroid Diseases Association

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 thyroid dysfunctions, partners with health professionals, and intervenes to assure the interests of these patients.

Many activities taken place over the years, with their highest point 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.

This year, we will be doing free screenings for Hypothyroidism to the Portuguese population to alert people for the important need of early diagnosis, supported by renowned endocrinologist doctors.

Additionally, we will be doing a series of activities, such as TV interviews, social media presence, partnership with local influencers, surveys and Webinars.

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

A Associação Portuguesa de Doenças da Tireoide (ADTI) foi fundada em 2012 com o intuito de apoiar os doentes e as suas famílias. Apoiar os interesses dos doentes da tireoide e representá-los é a principal missão da ADTI, que também apoia e esclarece sobre as disfunções da tireoide, colabora com profissionais de saúde e intervém para garantir os interesses destes doentes.

Muitas atividades foram feitas ao longo dos anos, com o seu ponto mais alto na Semana Internacional da Tireoide, quando, em parceria com outras organizações e instituições, conseguimos levar ainda mais longe a mensagem sobre a importância da tireoide e a necessidade de uma maior atenção à sua saúde.

Este ano, vamos fazer rastreios gratuitos de Hipotireoidismo à população portuguesa para alertar as pessoas para a importante necessidade de diagnóstico precoce, apoiado por médicos endocrinologistas de renome.

Além disso, estaremos realizando uma série de atividades, como entrevistas na TV, presença nas medias sociais, parceria com influenciadores locais, pesquisas e webinars.

Os membros da Direção da ADTI, bem como médicos endocrinologistas de renome e outros especialistas, trabalham na associação para a causa, ou seja, todos eles são voluntários.





Group picture at the annual meeting of the TFC in **Toronto, Canada, 1995**, where TFI was founded.



First TFI booth during the 24th annual meeting of the European Thyroid Association in **Munich, 1997**.



Ralph Abramsky, Diana Abramsky – TFI Founder, and June Rose Beaty – Editor from 1998-2008 (**Toronto 1995**).



TFI 2009 Annual Meeting – Lisbon, Portugal, 2009:

Taking a break from an intense and hardworking TFI meeting. (L to R) Standing: Peter Lakwijk, Netherland-Sweden; Harald Rimmele, Germany; Yvonne Andersson, Sweden, President TFI; Dr. Ulla Slama, Finland; Dr. Geraldo Medeiros-Neto, Brazil; Jytte Flamsholt, Denmark; Beate Bartès, France; Nancy Patterson, USA and sitting Ashok Bhaseen, Canada.



Warsaw 2001: Dr David Cooper (US) & son, Larry Wood, Shann Wood



TFI: 11th Annual Conference, Buenos Aires, Argentina 2005: Australia, Canada, Denmark, Finland, France, Russia, The Netherlands, United Kingdom, United States

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History of ThyroWorld

The history of Thyroid Federation International is written about on other pages. Our “ThyroWorld” newsletter has always been, and still is, aimed at the members of our member organizations. At the same time, the focus has extended to the attendees of thyroid conferences around the world: European Thyroid Association, American Thyroid Association, Latin-American Thyroid Association and Asian-Oceanian Thyroid Association.

Many of these attendees are now well aware of Thyroid Federation International – so the focus is further extended to the colleagues of the attendees. Over the years, we found that many attendees spread their knowledge to their colleagues who do not attend these conferences.

All articles are evidence-based and checked by members of our Medical Advisory Board. The level is meant to be easily readable for patients and for less specialized medical professionals.

June Rose Beaty was the editor from 1998 to 2008. In the first issue of ThyroWorld, June started with:



June Rose Beaty sadly passed away in 2019.

From the Editor's Notebook

ThyroWorld – the first issue of our newsletter – is at last in print. To see it through its production and publication has been no easy task. It's amazing, even in these days of sophisticated electronic communication, how many problems crop up and glitches creep in. Fax machines don't work properly, WP disks are not always compatible, photocopies become illegible and then there's always the factor of human error. But, of course, there's also the great bonus of human effort.

With material coming in from all over the world, many people were involved in getting this first issue off the ground. Kudos to Sally Mitchell of the UK for conceiving the idea and for assembling much of the original material which Ann Rigby-Jones processed and sent off on diskette to Canada. Sally also shepherded a first draft through discussion at the Munich meeting. And here we must think about our contributors, especially our German colleagues for their fine contributions to this first issue. Rhoda Boyce, acting as Canadian courier and contact, arrived back from Munich with tons of material – minutes, articles, stories, press releases and pictures – all of which had to be read, sorted and decisions made. What goes in, what stays out?

The national office of the Thyroid Foundation of Canada in Kingston, Ontario became the central clearing house for this material. Katherine Keen, Administrative Co-ordinator for TFI, did sterling service in tracking it all and in doing much of the word processing, ably assisted by Shelley Cohen-Shneider in Ottawa.

Much as we would like to have a multilingual newsletter, the decision was made to publish ThyroWorld in English, an international language. Indeed, we had enough problems whipping one language into shape as well as coping with the occasional problem of translation from German.

“ThyroWorld – the first issue of our newsletter – is at last in print. To see it through its production and publication has been no easy task. It's amazing, even in these days of sophisticated electronic communication, how many problems crop up and glitches creep in. Fax machines don't work properly, WP disks are not always compatible, photocopies become illegible and there's always the factor of human error. But, of course, there's always the great bonus of human effort.”

TFI history (TW 1998)
- From the Editor's Notebook

How the (Thyro)World has changed!

No more problems with fax machines, WP (WordPerfect for the younger readers) and photocopies.

We are all digital now. This issue is the first that will not be printed on paper but will be available in digital form; it is even distributed in digital conference bags.

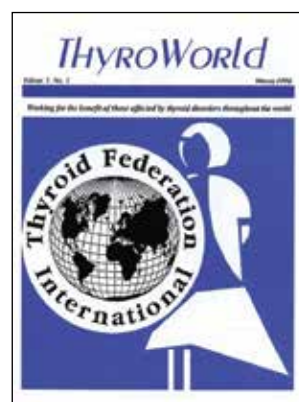
It still is not an easy task to come to publication, as we found new struggles with emails and conference programs like Zoom and Teams.

Other challenges are the people: “authors to write articles, timelines and, last but not least, the members of TFI”.

The content of ThyroWorld has not changed so much. Contributions from our members, articles about different thyroid issues and about the conferences we took part in. The major change is the amount of information. In 1995 we started with 6 member organizations and now it's nearly 35 from all continents (except Antarctica). The first ThyroWorld was 20 pages, the last was 40 pages. The first was in great part filled by the editorial board, for the last we had to select which articles to use to keep it within our limits.

Most of the earlier ThyroWorlds can still be read through the internet on our website:
<https://www.thyroid-federation.org/media/#world>

And we still follow the slogan published in our first edition in 1998: “Action is the difference between “Why” and “Why not”!



Cover of first issue of ThyroWorld in 1998.

A Backward Glance: A Forward Look

It was a warm September Sunday morning in Toronto, Canada, 1995. The 11th International Thyroid Congress was winding down as was the annual general meeting of the Thyroid Foundation of Canada. Meeting - weary as we were, there was still one more to go - an informal invitation to meet over coffee and discuss the “possibility” of some kind of international thyroid group.

So a couple of dozen people crowded into a small conference room of a downtown hotel - and that's where the Thyroid Federation International was born.

Of course, it had existed long before as a dream in the minds of Diana Abramsky, Larry Wood and others. But Toronto witnessed its actual birth.

As individuals and representatives of our respective thyroid organisations,

we all had enough on our plates to keep us busy but there was something so appealing about the idea of an international thyroid group, of sharing information with other organisations, of tackling worldwide thyroid problems, of helping thyroid sufferers that we couldn't refuse. And when babies and children were mentioned - well, we were hooked!

Six thyroid organisations from five countries were represented at that 1995 inaugural meeting. Canada, USA, Italy, Germany and the UK were soon joined in 1996 by The Netherlands and Australia and in 1997 by Denmark and Sweden.

The second meeting in Amsterdam in August 1996 was well structured and successful. Mission statements and goals were drafted, committees set up and officers elected.

Now, the third annual meeting in Munich is under our belt; we are growing in confidence, in projects and in numbers, ten member organisations. And we have launched ThyroWorld, the first issue of our newsletter.

With our newsletter name and logo, it is only fitting that we are on the World Wide Web, already a source of international information and communication.

All in all, not a bad track record for a very young organisation! We intend to keep on growing in our efforts to spread information about thyroid disease and to help those who suffer from it.

JRB

Action is the difference between why and why not!!

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WINTER 1998

TFI history (ThyroWorld 1998).

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
stofskifteforeningen.dk

ECUADOR*

*Ecuadorian Society of Endocrinology,
Metabolism, Diabetes and Nutrition*

EGYPT*

Egyptian Thyroid Association
<https://www.facebook.com/>

FINLAND

Suomen Kilpirauhasliitto ry
www.kilpirauhasliitto.fi

FRANCE

Association Vivre sans Thyroïde
www.forum-thyroïde.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
mct8.info

GREECE

Hellenic Thyroid Patients Organization

HONDURAS – AHCAT

Cancer de Tiroides Honduras
[www.facebook.com/
cancerdetiroideshonduras](http://www.facebook.com/cancerdetiroideshonduras)

INDIA*

*South Asian Federation of Endocrine
Societies*

INDONESIA

Pita Tosca
pitatosca.org/

ITALY

*CAPE –Comitato delle Associazioni dei
Pazienti Endocrini*
capeitalia.com

IVORY COAST

*Association des Malades de la Thyroïdes
de Cote d'Ivoire*
amtcotedivoire@gmail.com

KENYA

*Thyroid Disease Awareness Kenya
Foundation*
tdakfoundation.org/

MEXICO

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

NEPAL

Thyroid Foundation of Nepal
nepal@thyroid-federation.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*

Philippine Thyroid Association
philippines@thyroid-federation.org

PORTUGAL

*Associação das Doenças da Tiróide
(ADTI)*
www.adti.pt

SERBIA

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

SOUTH KOREA

Korea Thyroid Association (KTA)
south_korea@thyroid-federation.org

SPAIN

*Asociación Española de Cáncer de
Tiroides (AECAT)*
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



* Affiliated Member