



Thyroid
Federation
International

Thyroid Patients Worldwide

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Thyroid Federation International

Established in September 1995 in Toronto, Canada

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

Mentor & First President

Dr. Lawrence C Wood (USA)



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Website Coordinator: info@thyroid-fed.org

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Message from the Editors

Welcome to the 2023 edition of TFI's annual newsletter and welcome to Milan! TFI is delighted to partake in the 45th Annual General Meeting of the European Thyroid Association. TFI has been present at the meetings of the ETA since 1998.

TFI celebrated its 25th anniversary in 2020. From 6 founding members when the organization was created in Toronto back in 1995, it has now grown to nearly 40 member organizations in all parts of the world! We encourage everyone who provides evidence-based information to thyroid patients to apply for membership. We are very glad to welcome patient-led and patient oriented organizations.

In this magazine, you will find several articles from different sources. Sometimes these are readily published, sometimes they must be adapted to a patient level, and at times, the articles must be condensed to fit in the available space.

TFI is based on volunteer work and we pride ourselves on doing a great job these past years, with a very small team. We take part in conferences, sometimes just with a table and sometimes with lectures for the attendees. During the pandemic, these conferences were digital and didn't need travelling. This year we are glad to say, TFI's volunteers have participated in-person in nearly 20 conferences on all continents.

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

BEATE BARTÈS, PETER LAKWIJK, LINDA HENDERSON
AND NANCY HORD PATTERSON, EDITORS



Beate Bartès



Peter Lakwijk



Linda
Henderson



Nancy Hord
Patterson

ThyroWorld

Deadline for the next issue: June 20, 2024

Send all submissions to:

The Editors, ThyroWorld

Thyroid Federation International

Transpolispark

Siriusdreef 17-27

2132 WT Hoofddorp

The Netherlands

Email: tfi@thyroid-fed.org

Internet: www.thyroid-fed.org

President's Message

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



Ashok Bhaseen

Dear ETA delegates,

Thyroid Federation International is a 28 years young organization with 40 members in 36 countries across the globe. This year we celebrated the 15th Thyroid World Day, created by Thyroid Federation International, together with the International Thyroid Awareness week.

2023 has been a landmark year for TFI, as for the first time we were part of International Thyroid Awareness Week commemorations in Western Africa with Thyroid Ghana Foundation, in Accra, Ghana, along with TASI Nigerian Thyroid Foundation. It was also a great opportunity to understand and appreciate the need of such organizations that bring so much of value to the thyroid patients in Africa.

It was also a landmark year for TFI to participate in conferences across the globe related to thyroid diseases and learn and understand the need and synergy that patient organizations generate along with physicians and the industry. The synergy will result in better health outcomes for patients.

TFI is working with several thyroid associations, societies, patient groups, organizations for rare diseases, the world iodine network and the European Union on some joint initiatives.

Thyroid Federation International, despite being a truly global organization, is totally a volunteer-based organization. More than ever, non-profit volunteer organizations need the tools and skills to directly engage fellow patients and foundations and to cultivate a strong base of supporters. We are here to help you do that.

We are committed to building the tools and sharing the knowledge and best practices that our member organizations need to succeed.

We are also passionate about building awareness amongst thyroid patients of the importance of organizations like ours. The grants and support from various organizations and partners are making a vital difference in the lives of fellow thyroid patients around the globe, for this and future generations. We at TFI want to do our part, and we will continue to collaborate and support as many thyroid foundations, societies and associations as possible in the unique work they do that makes a difference to their fellow country thyroid patients.

I wish you and your families all the very best for the rest of 2023.

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



Ashok with Uruguay Delegates at LATS 2023

Petition: Open Access for Patients

Background

In 2015 the World Health Organisation (WHO) made it unambiguously clear that researchers have an ethical imperative to make results from all clinical trials – including past trials – publicly available. Its Statement on Public Disclosure of Clinical Trials Results:

- says results from clinical trials should be publicly reported within 12 months of the trial's end;
- calls for results from previously unpublished trials to be made publicly available, and;
- calls on organisations and governments to implement measures to achieve this.

(continued on page 4)

Petition: Open Access for Patients (continued from page 3)

Although it is important for clinical trials it is also important for scientific surveys with patient involvement.

The scientific and medical publishing systems continue to operate under systems which apply paywalls. When medical papers are behind paywalls, patients do not have access. At one point, some journals offered a patient access option, but we haven't seen that in a long time. Further, ordinary doctors, GPs, also do not have access. They might sometimes be able to gain access by going through the health systems, universities or hospital libraries. But this is simply unfeasible for regular access.

Therefore, potentially important information is locked away. Whether that could make life a bit more enjoyable, significantly improve quality of life, or is life-saving, all are important to the individual. This isn't an academic issue, in any sense, it is very real to many patients.



Patients have limited means for addressing this issue. One of the few is to refuse cooperation in research, which is not, will not, be published Open Access.

We ask all researchers and academics to support these ground rules:

- First, all patient consent requests require to state whether resulting publications will be Open Access. If not, it needs to be expressly asked whether the patient consents to publication behind a paywall. If there is no consent of publication behind a paywall, this will cause selection bias. This applies for all patient surveys as well as other research with patient involvement.
- Second, surveys and research which has been done with selection bias is not trustworthy. Once there is selection by Open Access vs. paywall, it undermines any claimed openness of selection criteria.
- Third, as a matter of principle, derivative papers should also be Open Access.

CONFERENCES AND CONGRESSES

TFI AGM 2022

After 2 years during which, due to the pandemic, our AGM had to be organized solely online, at the occasion of the 2022 ETA meeting in Brussels we were very happy to be able to meet again face-to-face. We used the “virtual” experience from the previous years and organized the assembly 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. It was attended by the representatives of our member organizations, and also by interested patients and endocrinologists from various countries. The members presented their organizations, and we also had presentations from medical professionals and a pharmaceutical company. 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!



Participants to the 2022 AGM, on-site in Brussels and online:

(From left to right and from top to bottom)

On screen: B.C. Surendra (Nepal), Faridul Alam (Bangladesh), Anna Bokor (Social Media Coordinator), Iruoma Ofortube (Nigeria).

On site: Peter Lakwijk (Sweden), Harald Rimmele (Germany), Linda Henderson (Italy), Nancy Patterson (USA), Beate Bartès (France), Ashok Bhaseen (Canada), Judith Taylor (UK), Nana Adwoa Konadu Dsane (Ghana), Teo San Luis (Philippines), Bojana Jedoksic (Serbia)

TFI – Events 2022-2023

ASHOK BHASEEN AND PETER LAKWIJK, TFI EXECUTIVE BOARD

Since the last Annual General Meeting in Brussels in 2022, TFI has attended several conferences, meetings and congresses in person or digitally.

This list of conferences that TFI attended doesn't show the real impact that this work has on the professional and patient world. Bringing knowledge about TFI to medical professionals is one of the most effective ways to get evidence-based information directly to the patients: not just in the member countries or by thyroidologists, but through all the endocrine professionals.

Many of these meetings took place in Europe:

European Society for Paediatric Endocrinology (ESPE), Italy, September 2022

For the first time 3 patient organizations were invited to take part in this conference. TFI met a whole new public of endocrinologists, pediatricians and pediatric nurses dealing with children and their mostly rare diseases, many of them related with the thyroid. There were nearly 1500 attendees.

International Clinical Trials Methodology Conference (ICTMC) United Kingdom, October 2022

This conference brought together 900 researchers and practitioners to present the latest news in trials methodology. TFI's interest to meet these researchers and practitioners is important, in order to be involved in trials for thyroid related diseases in an early stage.

World Iodine Association, Annual Meeting (WIA), Netherlands, November 2022

As member of WIA, TFI gave a presentation on the MotherBabyIodine project and gathered interest from organizations like WHO and Kiwanis.



Linda Henderson presenting, at WIA, Netherlands.

Drug Information Association Europe (DIA) Switzerland, March 2023

TFI attended this Multi-Stakeholders meeting with representatives of the regulatory Authorities, EU Commission, universities and other patient organizations to urge the need for the availability of drugs and the need for quicker access to new technologies and treatments.

Polish Endocrinology Society, Poland, March 2023 (online webinar)

The Chair Prof Artur Bossowski invited TFI to speak on the "Patient Perspective on Thyroid". The meeting was attended by Polish endocrinologists, internists, and pediatricians.

Reuters Pharma, Spain, April 2023

Reuters Pharma meetings is one of the biggest pharma meetings, where one of the core topic is "Patient Centricity". TFI was invited to hold a round table discussion on "Patient involvement and importance". TFI was the only Global Patient organization present among a huge Pharma gathering. This provided a greater awareness on our organization to the industry.

EURORDIS Annual Meeting, Sweden, May 2023

TFI is member of EURORDIS to give extra attention to the rare diseases that are related to the thyroid, and to work together with rare disease organizations in different countries in order to raise attention for thyroid-related rare diseases.

Peter Lakwijk with Simona Bellagmbi, EURORDIS, Sweden.



Peter Lakwijk with Gregory Randolph and Alison Waghorn, WCTC, UK.

(continued on page 6)

TFI – Events 2022-2023 (continued from page 5)**World Congress on Thyroid Cancer (WCTC), United Kingdom, June 2023**

The TFI booth had a lot of visitors from thyroid cancer specialists, like oncologists and surgeons, whom we do not meet at ATA, ETA, AOTA and LATS conferences. The interest to help in our patient tools and to participate in our webinars was high among the delegates who visited our TFI booth.

Thyroid Nodule Therapies conference (TNT), Italy, June 2023

TFI participated in this 2nd International Meeting on Ultrasound-Guided Minimally Invasive Therapies and presented the Patient Perspective, how it can help improve better outcomes by engaging the patients and teaming up. Many delegates visited our booth and want to work with TFI on future initiatives pertaining to thyroid nodules.



TFI Booth at TNT, Italy.

World Congress on Endocrinology and Diabetes (WCED), Portugal, July 2023

TFI was invited to speak at this conference on “Thyroid Dysfunction in Diabetic Patients”. The participants were mainly endocrinologists with a particular interest in diabetes, but also treating thyroid disorders. Most of these doctors do not attend ATA, ETA, LATS or AOTA and prefer this forum with both diabetes and thyroid. Those in attendance appreciated hearing the patient perspective and about the hereditary presence among their patient population. Also, the importance of adjusting the dose of thyroid hormone if both hypothyroidism and diabetes are present.



Peter Lakwijk with Bulent Yildiz, EndoBridge Turkey.

*In North America:***American Thyroid Association (ATA), United States, October 2022**

This annual conference gives TFI the opportunity to renew the contacts with many of the leading thyroidologists in the world and the thyroid pharmaceutical industry. ThyroWorld is always in the conference bags.

International Head and Neck Cancer Conference (HNCC), Canada, July 2023

At this conference, by the American Association of Cancer research and the American Head and Neck Society, leaders in the field presented their latest research and critical updates on head and neck cancer biology, detection, imaging, prevention, and therapy. TFI met here with American ENT surgeons and oncologists.

*In Asia:***EndoBridge, Turkey, October 2022**

TFI was invited to present themselves with a booth. We met many endocrinologists from the Middle East, Eastern Europe, North Africa and other parts of the world.

European Congress of Endocrinology (ECE), Turkey, May 2023

TFI is an affiliated member of the European Society of Endocrinology and was granted a free booth during the congress. TFI also presented “The Patient View” during the congress. TFI has a co-chair in the board of the ESE-PAG (Patient Advocacy Groups) with regular meetings with the chair of ESE to discuss upcoming events and matters of mutual interest. This year the ESE-PAG initiated surveys on availability of treatments in Europe and a petition on EDC (Endocrine Disrupting Chemicals).



Peter Lakwijk with Jérôme Bertherat, ESE President, ECE 2023, Istanbul, Turkey.

(continued on page 7)

TFI – Events 2022-2023 (continued from page 6)

In Africa:

International Thyroid Awareness Week (ITAW), Ghana, May 2023

TFI was invited by the Thyroid Ghana Foundation to participate in the 15th International Thyroid Awareness Week in May in Accra, Ghana. Also present was TASI, the Nigerian Thyroid Foundation. This was a landmark to show our commitment to the Thyroid Patients in Africa.

East African Diabetes Study Group (EADSG), Tanzania April 2023

There is still no African Thyroid Society, nor an Endocrine Society. The EADSG brings together endocrinologists from countries in the area. There was a lot of interest in the importance of patients (informing) organizations. TFI presented ways to get a patient (informing) organization going.



EADSG Tanzania: opening address by president Silver Bahendeka.



Interested public at EADSG, Tanzania.



Peter Lakwijk presenting at the EADSG in Tanzania.

In Latin America:

Latin American Thyroid Society (LATS) Brazil April 2023

This first LATS meeting after the pandemic broke all records of attendance, with 1700 delegates. Each delegate bag had the TFI logo and the ThyroWorld in it. TFI addressed the delegates at the congress and welcomed them to the booth. The interest in TFI was high and hence, we had visitors from Uruguay, Argentina, Columbia, Ecuador, Dominican Republic, Mexico, Paraguay & Peru apart from many Brazilian delegates, coming to the TFI booth to know more about our organization and how they can start in their own countries.

International Meeting of Pediatric Endocrinology (IMPE) Argentina March 2023

TFI attended this meeting online - there were over 1200 attendees (pediatricians from all over the world).



Ashok Bhaseen, TFI President addressing Reuters Pharma 2023 on Patient Perspective



Peter Lakwijk, Ashok Bhaseen, and Harald Rimmel at the World Congress on Thyroid Cancer.

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, and Lynda Wegner who diligently took care of the layout.

A special thank you goes to Giulia Giombolini, CAPE Italy, for all her help and time. We need more volunteers like Giulia!

Upcoming Events

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

ESPE, Sep 21-23, 2023

The Hague, Netherlands

ATA, Sep 27-Oct 1, 2023

ATA Washington DC

EndoBridge, October 19-22, 2023

Antalya, Turkey

AOTA, May 22-25, 2024

AOTA, Bali, Indonesia

ETA, Sep 7-Sep 10, 2024

Athens, Greece

ATA, Oct 30-Nov 3, 2024

Chicago, IL, USA

ITC June 18-22, 2025

Hosted by LATS, Rio de Janeiro, Brazil

WCTC, July 9-12, 2025

Boston, USA

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 21

World Iodine Deficiency Day

Band Keratopathy and Primary Hyperparathyroidism

We received an article by Kovacevic Bojan, Milic Ljiljana and Cuk Vladica of the University of Belgrade.

Full article at: <https://thyroid-fed.org/articles/acute-pancreatitis-and-band-keratopathy/>

The article is about the association between acute pancreatitis, band keratopathy and primary hyperparathyroidism (PHPT). Although this link is very unlikely, they report about a 34-year-old man who presented with clinical features of acute pancreatitis and band keratopathy both caused by primary hyperparathyroidism.

Acute pancreatitis is a condition where the pancreas becomes inflamed (swollen) over a short period of time. The pancreas is a small organ, located behind the stomach, that helps with digestion.

Band keratopathy involves calcium deposits that collect in layers of your eye's cornea. This can happen when calcium levels in your body are unbalanced.

In primary hyperparathyroidism, one or more of the parathyroid glands is overactive. As a result, the gland makes too much parathyroid hormone (PTH). Too much PTH causes calcium levels in the blood to rise too high,

which can lead to health problems such as bone thinning and kidney stones.

Pancreatitis caused by hyperparathyroidism is not a common entity, with low prevalence. The presence of PHPT can increase the risk of pancreatitis by almost 30 times as compared to the general population.

Band keratopathy describes the precipitation of calcium salts in Bowman's layer of the eye. Calcium salts are deposited intracellularly in patients with hyperparathyroidism as opposed to the extracellular deposits in patients with renal failure and in band keratopathy without elevated blood calcium.

In the case described, there is strong evidence that supports the fact that acute pancreatitis and band keratopathy are caused by primary hyperparathyroidism.

Conclusion

To the authors' knowledge, this is the third described case in the literature of concurrent acute pancreatitis and band keratitis as presenting signs of PHPT. More attention should be paid to the differential diagnosis in patients with hypercalcemia, abdominal and ophthalmological symptoms.

Iodine Basedow Syndrome

We received an article by Luljeta Abdullahu MD, Vjollca Dedushaj-Fazliu MD, PhD and Fitore Murati-Abdullahu PhD of the Department of Nuclear Medicine, University Clinical Center of Kosovo, Republic of Kosovo.

Full article at: <https://thyroid-fed.org/articles/iodine-basedow-syndrome/>

The article is about the challenges and dilemmas in Iodine Basedow syndrome thyrotoxicosis, and the influence of amiodarone.

The Iodine-Basedow phenomenon, the so-called Iodine-Basedow syndrome or thyrotoxicosis induced by large loads of exogenous iodine is rare.

The cause of thyrotoxicosis is an apparently contradictory phenomenon, after the administration of iodine or iodide, in the form of excessive iodide, by a dietary supplement, medical imaging with iodine contrast

or a drug, mainly amiodarone affecting the functioning of a normal thyroid gland.

Hyperthyroidism often occurs within 2 to 12 weeks after the administration of iodine. The iodine load is thought to result from impaired autoregulation.

A high incidence, 10-20%, of thyrotoxicosis is found in people with nodular goitre living in iodine-deficient areas, while a lower prevalence of hyperthyroidism, 1-20%, has been expressed after the introduction of iodine.

Iodine-Basedow syndrome may rarely occur in cases without thyroid disease, such as iodine-induced thyroiditis. Iodine-Basedow syndrome usually begins weeks or even months after the initial administration of iodine.

(continued on page 10)

Iodine Basedow Syndrome (continued from page 9)

A 67-year-old female is presented with symptoms that include fatigue, increased sweating, tachycardia, heat intolerance, restlessness and insomnia. She had frequent episodes of tachyarrhythmias and arterial hypertension, even though she has been on antihypertensive therapy for several years. After the diagnosis of the patient and an assessment Pronisone, antithyroid and beta blocker, was started and the patient felt much better and stable.

Amiodarone is a widely used anti-arrhythmic drug. A common long-term complication is amiodarone-induced thyrotoxicosis.

Each molecule of amiodarone has a significant structural similarity to thyroid hormones and contains two iodine atoms, which make up 37.5% of its mass. Therefore, a patient receiving a daily dose of 200 mg of amiodarone carries an amount of free iodine into the circulation that is 20–40 times higher than the daily iodine intake in the general population.

Amiodarone has a half-life of about 100 days, mainly due to its storage in adipose tissue, and toxic effects may persist.

This excessive iodine load generates significant adjustments in hormonal metabolism and physiological changes in serum thyroid function tests.

NEWS FROM THE THYROID FIELD

Thyroid Dysfunction and Risk Factors in Nepalese Diabetes Mellitus Patients

We received an article by Gandhi Prasad Sharma, General Secretary Thyroid Foundation of Nepal

Full article at:

<https://thyroid-fed.org/wp-content/uploads/2023/08/Thyroid-Dysfunction-in-Nepalese-Diabetes-Mellitus-Patients.pdf>

Diabetes mellitus is one of the greatest health threats for the 21st century all over the world. The prevalence of diabetes is rising rapidly in developing countries, and the global number of cases of diabetes is estimated to reach 366 million in 2030 among adults over 20 years of age. Both type 1 and type 2 diabetes are powerful and independent risk factors for Coronary Artery Disease (CAD), stroke, and peripheral arterial disease. The global rise in diabetes has led to a significant increase in health care expenditure.

There is a deep underlying relationship between diabetes mellitus and thyroid dysfunction. Studies have found that thyroid dysfunction is much more common in the diabetic population compared to the non-diabetic population. Most often, thyroid dysfunction and type 1 diabetes are due to an autoimmune condition, whereas type 2 diabetes is mainly due to insulin resistance. So, it seems that diabetes, especially type 1, has a potential link with thyroid dysfunction or vice versa. Besides the effects due to high blood glucose in diabetics, low thyroid hormones independently increase the risk for cardiovascular diseases in both diabetic and non-diabetic patients.

The latest reports suggest that diabetes is rising rapidly, particularly in developing countries from Asia.

A study in eastern Nepal reported diabetes in 6.3% of the population. Hence, assessment of thyroid function in the rising diabetic patient number may be helpful in identifying cases of clinical and subclinical thyroid dysfunction, thereby assisting in mitigating the harmful effects due to low thyroid hormones. The thyroid profile in the Nepalese population with diabetes mellitus has not been studied earlier. Thus, we designed a study by selecting confirmed diabetic patients from eastern Nepal and performed clinical and laboratory evaluation to investigate thyroid function status and associated risk factors.

In conclusion, the study identifies thyroid dysfunction, as well as prominently subclinical hypothyroidism, as a common disorder in Nepalese patients with diabetes. Diabetic patients with thyroid dysfunction had higher lipid levels (total cholesterol and LDL cholesterol) than patients without thyroid dysfunction, so diabetic patients with thyroid dysfunction are at higher risk for cardiovascular diseases than those with normal thyroid function. Similarly, smoking, family history of thyroid disease, and female gender were associated with thyroid dysfunction (mainly hypothyroidism) in the study population.

Thus, frequent screening for thyroid dysfunction especially in diabetic patients with family history of thyroid disease, female gender, and smoking habit needs to be done.

Iodization in India: Vigilance is Victory

SANJAY KALRA, PRESIDENT OF SAFES (SOUTH ASIAN FEDERATION OF ENDOCRINE SOCIETIES) AND DEPARTMENT OF ENDOCRINOLOGY, BHARTI HOSPITAL, KARNAL.

RAKESH SAHAY, DEPARTMENT OF ENDOCRINOLOGY, OSMANIA MEDICAL COLLEGE, HYDERABAD, INDIA.

Iodine is a non-metallic element, atomic weight 53, which occurs as a solid at room temperature. Iodine is used extensively in diagnostics, therapeutics and industrial production. Iodine is included as an essential medicine by the World Health Organization, and guidelines specify the importance of prescribing iodine-rich micronutrient preparations during pregnancy.

Iodine, in fact, is the heaviest element that is essential for life. Discovered by Bernard Courtois in 1811, it was renamed by JL Gay-Lussac in 1813. Around the same time, in England, Dr Mountfort Bramley was studying in school, preparing to join duty in faraway Kathmandu, Nepal, as a medical resident. Bramley conducted the first large-scale epidemiological study in Southern Asia and highlighted the heavy burden of goitre in Nepal and the surrounding Himalayan regions in 1833. He alluded to the possible connection of goitre with iodine deficiency.

At the same time, his contemporary Boussingault, working in present-day Colombia, advocated goitre prophylaxis with iodine-rich salt. Two decades later, Chatin, in Paris, hypothesized that goitre was caused by iodine deficiency. It took over seven decades, however, for Switzerland to start an iodized salt public health programme. This led to drastic improvements: the incidence of newborn goitre and cretinism came down to zero in the Canton of Appenzell, where the surgeon Eggenberger took the lead in popularizing iodized salt.

Indian researchers had sustained their interest in iodine and goitre. McCarrison R et al, writing in 1927, reported that there was no relation of endemic goitre with the iodine content on soil or drinking water in South India. They postulated that the essential cause of endemic goitre was poor hygiene, especially water pollution. Siddiqui, based upon the findings of a community-based survey in Nalgonda district, proposed that excessive fluorine intake contributed to goitre in iodine deficient settings. His contemporary, Patnaik, focused his work on determining iodine content of Indian foodstuffs, in order to improve iodine sufficiency.

The Kangra Valley, nestled in the north western Himalayas in present-day state of Himachal Pradesh, was the site of a landmark study, sponsored by the

government of India. Salt was iodized using potassium iodide and potassium iodate, and the population followed up for five years. Participants were examined for presence and severity of goitre, their salt and drinking water was analyzed for iodine content, and ¹³¹I thyroid uptake was measured in schoolchildren. The results were astounding. Goitre and iodine deficiency disappeared in the villages where salt had been iodized.

These results, shared by Sooch and Ramalingawamy with a global audience, helped the cause of iodine advocacy. They paved the way for nation-wide iodization of salt in India. The National Goitre Control Programme, launched in 1962, and later renamed the National Iodine Deficiency Disorder Control Programme in 1992, relied on universal salt iodization as a means of eliminating iodine deficiency disorders. Today, iodized salt is available across the length and breadth of the country.

Universal availability and accessibility of affordable iodized salt has helped eradicate iodine deficiency disorders. Data from the National Family Health Survey-5(NFHS-5) shows that West Bengal (94.5%), Bihar (93.3%), Karnataka (92.8%), Meghalaya (90.6%), Dadra & Nagar Haveli, and Daman & Diu (89.1%) as well as Andhra Pradesh (83.1%) have low levels of iodized salt consumption in their households. Though this is a great improvement over the 51% of households that reported use of iodized salt in 2006, it is not at 100%.

Across India, many individuals and communities exhibit a preference for non-iodized or rock salt. The reasons may be related to cultural and religious practices, or perceived culinary and health benefits. This is not surprising, because the current generation has no recollection of what iodine deficiency disorders looks like. In fact, there is a hypothesis that universal screening for thyroid dysfunction in pregnancy has made India a more intelligent country.

Each life is important, and each person must be protected from iodine deficiency disorders. Hence, we should not aim for less than 100% coverage of households with iodized salt consumption. We need to continue spreading awareness about iodine deficiency and iodine deficiency disorders; we need to remain vigilant if we are to be victorious in our fight against iodine deficiency.

As Wilson Pickett sings, “Ninety-nine and a half just won’t do”.

Sensitivity of Three Thyrotropin Receptor Antibody Assays in Thyroid-Associated Orbitopathy

MARIJA SARIĆ-MATUTINOVIĆ; TANJA DIANA; BILJANA NEDELJKOVIĆ-BELESLIN; JASMINA ĆIRIĆ; MILOŠ ŽARKOVIĆ; IVA PEROVIĆ-BLAGOJEVIĆ; GEORGE J. KAHALY AND SVETLANA IGNJATOVIĆ — BELGRADE (SERBIA)/MAINZ (GERMANY)

Full article at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9010037/>

Thyrotropin receptor autoantibodies (TSH-RAb) are indispensable biomarkers in the laboratory assessment of thyroid-associated orbitopathy (TAO). Clinical sensitivity of three different assays for TSH-R-Ab determination was evaluated in patients with TAO.

Eighty-seven consecutive TAO patients were enrolled and their serum samples analyzed in parallel with three assays. An ECLIA competitive binding and a chemiluminescent bridge immunoassay were used to measure total and binding TSH-R-Ab concentration, while their functional activity was determined using a stimulatory TSH-R-Ab (TSAb) cellbased bioassay.

Results

Compared to the two binding assays (ECLIA $p < 0.001$, bridge $p = 0.003$), the TSAb bioassay was more sensitive pertaining to the positive detection of TSH-R-Ab in TAO patients. No difference ($p = 0.057$) was noted between the ECLIA and bridge assays regarding sensitivity rate. All patients with active and/or moderate-to-severe TAO tested positive in the TSAb bioassay (100% and 100%, respectively), while the positivity rates for bridge and ECLIA binding assays were 89.7% and 82.1% for active TAO, and 90.2% and 86.3% for severe TAO, respectively. Negative predictive values of the bioassay, bridge, and ECLIA assays were 100%, 75%, and 71%, respectively for active TAO, and 100%, 86%, and 71%, respectively for moderate-to-severe TAO. The superiority of the bioassay was most prominent in euthyroid (ET) TAO. Positivity rates of the TSAb bioassay, bridge and ECLIA binding assays were 89.6%, 75%, and 64.6%, respectively for inactive TAO; 86.1%, 69.4%, and 52.8%, respectively for mild TAO; 87.5%, 62.5%, and 12.5%, respectively for euthyroid TAO. The bridge assay correlated better with the ECLIA binding assay ($r = 0.893$, $p < 0.001$), compared to the bioassay ($r = 0.669$, $p < 0.001$).

Conclusions

The accuracy of a diagnostic method must be viewed from the perspective of the disease range and the context in which it is examined. Accordingly, the study design, as well as the choice of the appropriate statistical methods used, is usually defined by the intended purpose of the examined biomarker. The present study focuses on the clinical value of a new replacement test relative to the standard, commonly used test for TSH-R-Ab detection. We compared the diagnostic features of the TSAb bioassay and bridge binding assay in relation to the standard competitive binding assay. We examined the variability of their performance both in all TAO patients and relative to the activity, severity, and duration of TAO. Replacement was chosen as the most suitable purpose for this assay comparison.

Superior diagnostic characteristics, primarily high sensitivity rate of the serological TSH-R-Ab methods are an imperative for accurate and timely differential diagnosis of TAO. Highly sensitive methods are necessary for the adequate recognition of a variety of TAO clinical phenotype. For clinicians, this feature is of utmost importance, since it defines further steps in patient management. 100% sensitivity and 100% NPV for detection of active and moderate-to-severe TAO means that no such patient will remain undetected and that a negative test result will certainly exclude a progressive form of disease. These patients need to receive the appropriate therapy, and are more likely to develop sight-threatening TAO that requires an urgent treatment. Moreover, a reliable and noninvasive serological test is a feasible first-line solution, especially if thorough clinical assessment in tertiary care units is not readily available. High sensitivity of TSH-R-Ab tests has particular clinical value in case of euthyroid TAO, a challenging clinical condition often confused with various other inflammatory disorders. Differential diagnosis of ET TAO is especially complicated and depends entirely on serological confirmation of TAO.

Our present findings demonstrate somewhat better diagnostic performance of the bridge binding assay compared to the traditionally used ECLIA binding test, but evidently poorer in comparison to the TSAb bioassay

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Sensitivity of Three Thyrotropin Receptor Antibody Assays (continued from page 12)

technique. Only in active TAO patients, the bridge assay performed similarly to the bioassay, although a small number of patients was involved. Interestingly, in neither of TAO patient groups, the bridge assay was significantly more sensitive than the ECLIA binding assay. In contrast, the functional bioassay showed markedly higher clinical sensitivity rate relative to the binding assay in all examined patient groups. The bioassay superior diagnostic sensitivity relative to both binding immunoassays was the most prominent in patients with milder clinical presentation of TAO (inactive TAO, low-positive TSAb). This suggests that the bioassay would be a better choice in management of atypical forms of TAO, without signs of inflammation and thyroid abnormalities. In line with this, the variability of the clinical features was especially notable in ET TAO patient group, where only bioassay demonstrated a satisfactory positivity rate, i.e. the ability to detect virtually all ET TAO patients.

Dual stimulating and blocking antibody activity was observed in one GD patient. However, this patient tested negative in the bridge binding assay. Potential explanation lies in the variable affinity and concentration of TSAb and TBAbs, possible mutual neutralization of the

antibodies, as well as the specificity issues of the chimeric TSH-R construct used.

We demonstrated superior clinical performance of the bioassay method compared to the traditionally used competitive binding ECLIA assay and the new bridge assay technique, primarily in terms of clinical sensitivity.

Bridge assay performance was positioned somewhere in the middle and as such wouldn't be a suitable replacement for the commonly used binding method.

In this way we strived to meet the clinicians' needs that are to maximize the sensitivity of the tests so as not to miss any TAO patient, especially those with mild and nonspecific presentation of the disease, as well as those who need to receive the appropriate treatment. According to these findings, as well as the clinical goals, we conclude that only the bioassay demonstrates sufficient diagnostic characteristics to replace the existing competitive binding assays where possible.

Integration of bioassays into the current diagnostic algorithms of TAO could substantially improve patient management, monitoring, and prediction of clinical course of disease.

NEW FROM THE THYROID FIELD

Health Care Access of Thyroid Disease Patients in Serbia during the COVID-19 Pandemic

M. ŽARKOVIĆ; P. PERROS; J. ĆIRIĆ; B. BELESLIN; M. STOJKOVIĆ; M. MILETIĆ; AND T. JANIĆ — BELGRADE (SERBIA)/NEWCASTLE UPON TYNE, UK

For the full article:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8944403/>

The Coronavirus Disease 2019 (COVID-19) pandemic proved to be a serious challenge to health care delivery globally. Both the number of patients needing medical care and the constraints of lockdown posed significant difficulties in accessing health care. A Canadian survey of dermatology patients showed that only one-third was able to obtain in-person appointments. In Poland, access to cancer diagnostic and treatment services declined during the pandemic. A retrospective study showed that the implementation of measures aimed at creating capacity for COVID-19 admissions was associated with a 60% decrease in cancer-related surgery. In contrast, patients with diabetes

in Singapore had unrestricted access to healthcare, medicines, and supplies. Therefore, access to healthcare during the pandemic varied depending on both diagnosis and geographic location.

Data on the impact of the pandemic on services and health care of patients with thyroid diseases are scarce. Thyroid cytology reports declined drastically in 23 countries (not including Serbia). The prospective data on thyroid surgery and thyroid diagnostics in China showed a significant influence of COVID 19. The number of fine-needle aspiration biopsies (FNAB) and thyroid surgeries was significantly reduced. This was especially pronounced in the period from 25 January till 25 February when COVID 19 alert level was raised to the highest level. During this period, no FNAB or thyroid surgeries were performed. An Italian study found that adaptation of the services for patients with thyroid cancer using telemedicine resulted in only a minor reduction (15%) of consultations compared to the previous year.

(continued on page 14)

Health Care Access of Thyroid Disease Patients in Serbia (continued from page 13)

European countries are unavailable. In Serbia, one of the government responses to the COVID-19 pandemic was the conversion of general to the COVID-19 hospitals and transfer of staff to the COVID-19 facilities.

Our data show a considerable influence of the pandemic on the treatment of patients with thyroid disease. The main problem was the lack of access to specialist care. About 50% of the respondents could not reach specialist care, and a further 30% had difficulties in accessing specialist care. The pattern of reduced access to specialist care during pandemics is also observed in other countries and specialities

During the pandemic lockdown, increased anxiety and reduced quality of life were reported by patients with thyroid disease in the UK. In our sample, we confirmed a significant degree of concern regarding medical care caused by the pandemic.

Although the main source of information for our respondents was through web searches, social networks and physicians were utilized by a considerable number of patients. This shows that physicians can have a substantial influence on the information that patients receive.

Thyroid disease is the second most common component of the workload of European endocrinologists. Therefore, it can be argued that the impact of the pandemic on health care access of patients with thyroid diseases also indirectly reflects the

experience of patients with other endocrine diseases.

One of the drawbacks of this survey is that it is unclear how representative our sample was. In our sample, the proportion of responders with a level of education not higher than elementary was 5.4% compared to 34.4% reported by the Serbian Statistics Office. Another notable characteristic of our sample was that majority of patients (77.5%) had already a previous diagnosis before the pandemic mostly hypothyroidism, with a treatment duration of over 6 years, and had received regular medical follow-up. This would tend to underestimate difficulties with access to health care.

In conclusion, the COVID-19 pandemic disrupted the medical care of thyroid patients in Serbia. For the patients treated in the public health care system, access to general practice was hindered, while access to specialist care was disrupted. It led to a switch from public to private health care, which was perceived as a financial burden for almost all the respondents. However, private health care proved to be an important safety net when the public system was overwhelmed.

Reference:

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NEW FROM THE THYROID FIELD

Thyroid Autoimmunity and Pregnancy

SANJA MEDENICA, ASSOC.PROF SANJA MEDENICA,
DEPARTMENT OF ENDOCRINOLOGY, INTERNAL
MEDICINE CLINIC, CLINICAL CENTER OF
MONTENEGRO,
UNIVERSITY OF MONTENEGRO, FACULTY OF
MEDICINE, PODGORICA, MONTENEGRO



Thyroid autoimmunity (TAI) is a disorder of immune tolerance to one's own antigens, such as thyroglobulin (Tg) and thyroid peroxidase (TPO). It is the most common disease of the thyroid gland in the reproductive period. As very well-known, TAI is related with infertility, affecting folliculogenesis, fertilization, embryogenesis, and implantation but as well related to numerous maternal and fetal complications. Thyroid autoantibodies are an independent marker of failed assisted reproduction (ART) outcomes. Follicular fluid (FF) is the important microenvironment for oocyte quality.

The first study we did was in order to assess the association of the levels of thyroid autoantibodies in FF and ART outcome, enrolling 52 women undergoing ART, 26 TAI positive, and 26 age and body mass index matched TAI negative controls. The study verified the presence of thyroid autoantibodies in FF of TAI positive women undergoing ART, and assessed their impact on achieving fertility. We concluded that thyroid autoantibodies present in FF are not generated in the FF, but cross from the blood. For the first time we showed that concentrations of thyrotropin (TSH) and free thyroxine (fT4) in FF are the same in women with and without TAI. TAI did not directly impact oocytes and embryos during ART treatment, but it may have an effect on the post-implantation embryo development. Our results indicated lower ART success rate, expressed as the

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Thyroid Autoimmunity and Pregnancy (continued from page 14)

achieved pregnancies, in women with TAI highlighting the importance of TAI diagnosis in women presenting with infertility.

Further, we made a step forward in estimating the pregnancy and newborn outcomes in the group of women with confirmed clinical pregnancy. Pregnancy outcome rates were as following: twin pregnancy rate 41.7%, early miscarriage rate 8.3%, late miscarriage rate 4.2%, preterm birth rate 16.7%, term birth rate 70.8%, live birth rate 96.0%. The results pointed to the importance of partly neglected thyroglobulin antibodies. Newborns of women in the TAI positive group had higher birth weight and height. Maternal complications occurred in 23.8% of patients, and no congenital malformations in newborns were noted. Thus, we concluded that thyroid autoantibodies present in FF may have an effect on the post-implantation embryo development but have no effect on the further course of pregnancy. In both studies we emphasized the importance of intracytoplasmic sperm injection method of fertilization in TAI positive women for better fertilization rate.



Symposium on thyroid gland and pregnancy with international participation held on June 2nd, 2023 in Podgorica, Montenegro

When it comes to levothyroxine treatment, controversies are still present, but the results of the last major trials indicate that the use of levothyroxine in euthyroid women with TAI did not result in a higher rate of live birth or in a lower rate of miscarriage than placebo. Cell and gene therapies hold great potential for treating autoimmune conditions such as TAI.

NEW FROM THE THYROID FIELD

Transforming Thyroid Ablation:

Harnessing tomographic 3D ultrasound technology for enhanced patient experience

DR. ERIVELTO VOLPI
HEAD AND NECK DEPARTMENT, ONCOLOGY CENTER, OSWALDO CRUZ GERMAN HOSPITAL, SÃO PAULO, BRAZIL

With a prevalence of up to 70% among the population over fifty years old, thyroid lesions are common. A thyroid lesion refers to an abnormal growth or lump in the thyroid gland, a small, butterfly-shaped gland located at the base of the neck. Thyroid lesions can range from small, benign nodules that cause no symptoms to larger, possibly cancerous growths.

For a long time, state-of-art treatment for thyroid lesions was surgical resection, the so-called thyroidectomy. In the 1940s, radioiodine therapy was introduced as an alternative method for treating overactive thyroid conditions like hyperthyroidism and certain types of thyroid cancer. Since the 1990s, various additional minimally invasive treatments, particularly thermal ablation techniques, have been gaining popularity in treating thyroid nodules. The two most commonly used methods are Microwave

ablation (MWA) and radiofrequency ablation (RFA), where these heat sources are applied through a needle to destroy the abnormal tissue by heat, preserving the surrounding healthy thyroid tissue. Both methods are associated with lower complication rates than traditional surgery, less scarring, no need for hospital stay, and significantly faster recovery time. The main long-term benefit for the patient, however, is the preservation of the thyroid and functionality. In contrast to traditional thyroidectomy, the patient is usually not required to manage hypothyroidism by taking daily thyroid hormone replacement therapy.

About two years ago, a new 3D imaging technology was introduced by the Austrian company PIUR IMAGING GmbH that can support the selection process of patients suitable for thermal ablation, patient education, and procedure planning. The tomographic 3D ultrasound solution “Infinity” is an add-on to standard ultrasound devices that allows the acquisition of volume ultrasound data of the thyroid with a regular

(continued on page 16)

Transforming Thyroid Ablation (continued from page xx)

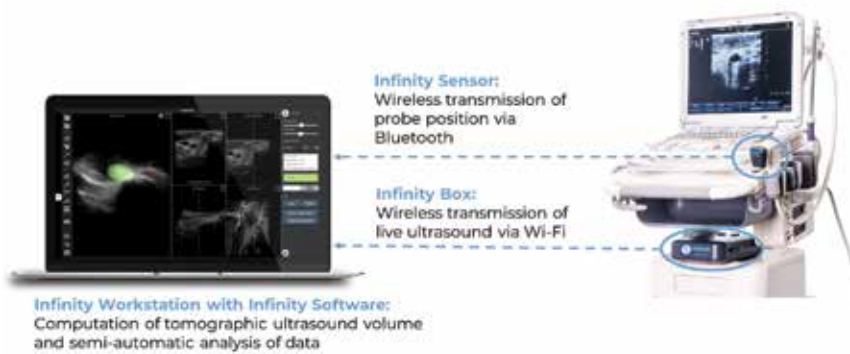


Figure 1: Setup and components of PIUR's Infinity system

2D ultrasound transducer (Figure 1). The system consists of a video box that can be connected to the video output of any third-party ultrasound system. It wirelessly transfers live ultrasound images from the ultrasound to a stand-alone workstation that collects the image information for later processing. The second part of the Infinity is a wireless sensor that can be attached to the ultrasound transducer through a bracket. The sensor measures transducer movements during a freehand ultrasound acquisition and sends this information to the workstation. The proprietary software combines image and sensor information to estimate the probe trajectory during the freehand acquisition, which is then used to perform a volume reconstruction of the images. This solves some of the main shortcomings of traditional ultrasound: image documentation, lack of volume information, and transparency of diagnostic results.

The system is more than an image acquisition device; it is also a computer-aided solution that supports the user with the diagnostic workflow of thyroid and nodules, including image analysis and reporting. The solution automatically identifies the thyroid lobe and calculates its volume. With additional user input, thyroid nodules can be marked, quantified, and visualized as multiplanar reconstructions or 3D volume renderings. On top of that, the solution calculates and proposes the five ACR TI-RADS parameters to the user to classify the nodule.

This results in several benefits for the physician and patient throughout treatment. Before the ablation procedure, the Infinity enables healthcare professionals to precisely determine the thyroid nodule's size, location, and characteristics. This crucial information ensures appropriate patient selection and facilitates optimal treatment strategies. Dynamic 3D visualizations of the thyroid and thyroid nodules help patients better understand their condition and the planned ablation procedure. Instead of plane greyscale images and hand-drawn sketches of the lesions, the physician can explain the situation to the patient with real 3D renderings that can be rotated and manipulated. This helps with communication before treatment and allows the

patient to understand the treatment's effectiveness over time. 3D scans can be performed before and after treatment to provide the patient with a side-by-side comparison of the evolution of the nodule before and after the ablation (Figure 2).

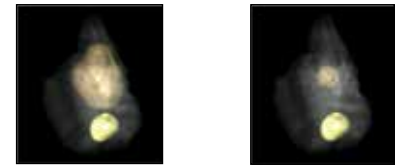


Figure 2: Before RFA treatment (left) and 12 months after RFA treatment (right)

Tomographic 3D ultrasound is a promising technology that will further facilitate the acceptance and penetration of innovative ablation technologies. It not only enhances the patient experience, but also objectifies diagnostic results and makes the decision criteria for selected treatment procedures transparent and documentable.

LATS Conference 2023



Ashok Bhasen, TFI President with President LATS Fabian Pitoia and Renato Oliveira at LATS, June 2023

Multimodality Management of Immunogenic Primary Hyperthyroidism in India

ORIGINAL ARTICLE FROM PRESIDENT AND HONARY SECRETARY OF THE THYROID & ENDOCRINE FOUNDATION OF INDIA

M. S. SENTHIL KUMAR¹, E. PRABU², MANOHARAN³, SUBASHINI⁴, PARANTHAMAN⁵, MONISHA⁶



Full article at:

<https://thyroid-fed.org/wp-content/uploads/2023/08/Multimodality-Management-of-Immunogenic-Primary-Hyperthyroidism-in-India.pdf>

Graves' Disease is treated across the globe predominantly with medical treatment by physicians. However, many treatment strategies evolved with the latest advances whereas the modalities of treatments differ from the stage of the disease, the treatment outcome, treatment response, severity, nodularity, volume and ophthalmopathy.

Graves' Disease (Primary thyrotoxicosis) or immunogenic Primary Hyperthyroidism is a disease process which may manifest with the onset of ophthalmic component with prominent eye signs otherwise called exophthalmos or with goiter preceding the onset of eye signs. The erstwhile diagnostic feature of exophthalmos indicating a definitive diagnosis of Graves' needs rethinking since the onset of disease does not correlate to the onset of symptoms or proptosis which may precede or follow goiter formation. Eye signs are not pathognomonic of Graves' since they can also occur in a small percentage of large multinodular goiter and may be equivocal in appearance in thyroiditis especially Hashitoxicosis where Scintigraphy may be useful. There is a genetic preponderance where females less than 35 are affected but we have come across a cross section of men afflicted by Graves' Disease worsened by smoking. Cessation of smoking needs to be advocated as an immediate measure for successful control of the toxicity. The predominant symptoms and signs of Graves' are well known and widely discussed in literature. The pathology of Graves' Disease is a predominantly autoimmune process resulting in overproduction of thyroid hormone and excess circulation of the overproduced thyroid hormone. The eye signs are tabulated and analysed employing the well accepted clinical activity score. To undertake surgery the specific indications in Graves' Disease are nodule formation, refractory to medical treatment, large volume beyond the critical mass limit and recurrence after low dose radio ablation. Scintigraphy was utilized not to diagnose Graves' Disease but to assess severity and rule out cold nodules and thereby malignancy.

The treatment modalities for Graves' are medical management, radioactive ablation, and in some cases surgery.

Medical treatment depends on the onset of symptoms and, depending upon the severity, we initiate treatment with antithyroid medications like Carbimazole, Methimazole, propylthiouracil and beta blockers along with supportive treatment and nutrition. In India we also use Holter monitor to study and monitor cardiac rhythm.

The clinical improvement and clinical euthyroid is the goal of treatment and it will be achieved by sleeping pulse rate, assessment of proximal muscle weakness and weight gain. In addition, Holter monitors are employed by physicians' and cardiologists' assessment of echocardiogram, and mood disorders and mood swings are included in the treatment.

The treatment response is monitored by clinical outcome after a period of six weeks until six months. Thereafter it is deemed unresponsive to treatment or refractory depending upon the parameters of biochemical assessment.

Assessment of the severity of Graves' Disease is by either technetium 99 m scintigraphy or Iodine 131 Scintigraphy. Whenever it is uncontrolled Graves' Disease, some employ the addition of steroids. Radioactive ablation is a treatment option which depends upon the volume and echogenecity and sonologically diffuse pattern. In India when the volume is less than 30 ml and sonologically diffuse, then low dose radioactive ablation is a choice of treatment with less than 9 milli curies with customized isotope regimen than dosimetry. When there are eye signs as evidenced by clinical activity score then radioactive ablation is withheld.

The role of surgery is in the following situations:

- Whenever the volume of the thyroid gland is larger than 30 ml
- Whenever deemed refractory to medical treatment for a period of six months
- Whenever there is nodularity
- Whenever there is Marine-Lenhart syndrome

1- SENIOR ENDOCRINE FACULTY, DEPARTMENT OF ENDOCRINE SURGERY, MADRAS MEDICAL COLLEGE, CHENNAI, INDIA & SENIOR ENDOCRINE SURGEON- APOLLO HOSPITALS; 2 - SENIOR CONSULTANT, TN MULTI SUPER SPECIALTY HOSPITAL, CHENNAI, INDIA & SENIOR NUCLEAR PHYSICIAN; 3-PROFESSOR OF CARDIOLOGY, MADRAS MEDICAL COLLEGE; 4 - SENIOR CONSULTANT, PSYCHIATRY SCARF FOUNDATION; 5 - PROFESSOR OF INTERNAL MEDICINE, KILPAUK MEDICAL COLLEGE; 6 - ASST PROFESSOR OF GENERAL SURGERY ACS MEDICAL COLLEGE, CHENNAI

What Patients should know about Hypothyroidism

PROF FARIDUL ALAM. MD, PHD., VICE CHANCELLOR, BANGLADESH UNIVERSITY OF HEALTH SCIENCES, DHAKA, BANGLADESH; SECRETARY GENERAL, BANGLADESH THYROID SOCIETY: VC@BUHS.AC.BD



The thyroid gland is a butterfly-shaped endocrine gland that is normally situated in the front of the neck. It produces thyroid hormones, tetra-iodo-thyronin (T₄) and tri-iodo-thyronin (T₃). The Thyroid hormone helps the body to use energy, stay warm and keep the brain, heart, muscles, and other organs working. It also plays a vital role in the development of brain and body structure in fetal life.

How to help patients understand they are Hypothyroid

When thyroid hormone levels are too low, the body's cells do not have sufficient thyroid hormone and the body's metabolic activities are also lowered. Patients feel cold, tired, sleepy, low appetite, drier skin, becoming forgetful, depressed, and constipated. The symptoms are different in different individuals and nonspecific. Hypothyroidism is confirmed by a simple blood test for TSH. Patients should visit the doctor for further management. The family members should be informed. Because thyroid disease runs in families, it is important to explain hypothyroidism to relatives and encourage them to get periodic TSH tests.

Consequences of the disease

In general, hypothyroidism cannot be cured – but it can be completely controlled. There are exceptions as patients with viral thyroiditis have their thyroid function return to normal, as do some patients with thyroiditis after pregnancy. By taking medicine (thyroxin tablets) regularly, and following the advice of the doctor, it is possible to be free of serious effects of hypothyroidism and to have the same quality of life as the other family members.

Cause

Autoimmune thyroid disease (AITD): the immune system which protects the body from invading organisms, can sometimes mistake thyroid gland cells or their enzymes as invaders and can attack them. As a result, thyroid cells become sick and cannot produce sufficient hormone. The most common forms of AITD are Hashimoto's thyroiditis and atrophic thyroiditis. Both of these AITDs can cause hypothyroidism.

Surgical removal of part or all of the thyroid gland may be needed in case of suspicious nodules, large goiter,

thyroid cancer or Graves' disease. It may be necessary to remove part or all of the thyroid gland. If the whole thyroid is removed, the patient will definitely become hypothyroid. If part of the gland is left, it may be able to produce sufficient thyroid hormone to keep blood levels normal.

Radiation treatment might be required for Graves' disease, nodular goiter, or thyroid cancer. Treatment with radioactive iodine (I-131) is used for the purpose of destroying the thyroid gland. All these patients can lose part or all of their thyroid function and become hypothyroid.

Congenital hypothyroidism: Some babies are born without a thyroid or with only a partly formed one.

Medicines, such as amiodarone, lithium, interferon alpha, and interleukin-2, can prevent the thyroid gland from being able to make the hormone naturally. Taking in excess iodine can cause or worsen hypothyroidism.

How patients are diagnosed

Symptoms (described earlier) and family history are important. If doctors are informed of this, they will better understand what is happening. Patients should tell their doctor about any changes in their health that suggest the body is slowing down or if they have ever had thyroid surgery or if they have ever had radiation to the neck to treat cancer and what medicines they take, such as amiodarone, lithium, interferon alpha, interleukin-2, and possibly thalidomide. The doctor will check the thyroid gland and look for changes such as dry skin, swelling, slower reflexes, and a slower heart rate.

Blood tests

There are two blood tests that are used in the diagnosis of hypothyroidism, TSH and T₄. An abnormally high TSH means hypothyroidism: there is not enough T₄ in the blood.

Treatment

In general, hypothyroidism cannot be cured – but it can be completely controlled. It is treated by replacing the amount of hormone no longer produced by the thyroid, in order to bring T₄ and TSH levels back to normal. Synthetic thyroxine pills contain hormone identical to the T₄ made by the thyroid gland itself. For the few patients who do not feel completely normal taking T₄ alone, the addition of T₃ may be of benefit.

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What Patients should know about Hypothyroidism *(continued from page 18)*

Side effects

If patients take a dosage which is too small, hypothyroidism will continue. If they take too much, they will develop the symptoms of hyperthyroidism, an overactive thyroid gland. The most common symptoms of too much thyroid hormone are fatigue but inability to sleep, greater appetite, nervousness, shakiness, heat intolerance, and trouble exercising because of weak muscles, shortness of breath, and a racing, skipping heart. Patients who have hyperthyroid symptoms at any time during thyroxine replacement therapy should have their TSH tested. If it is low, indicating too much thyroid hormone, their dose needs to be lowered after consulting with the doctor.

Follow-up

Patients should have their TSH checked every 6 to 10 weeks after each change of their thyroxine dose; it may require tests done more often if the patient is pregnant or taking a medicine that interferes with the body's ability

to use thyroxine. The goal of treatment is to get and keep TSH in the normal range. Babies with hypothyroidism must get all their daily treatments and have their TSH levels checked as they grow, to prevent mental retardation and stunted growth. Once settled into a thyroxine dose, they can return for TSH tests about once a year.

If patients gain or lose a good amount of weight (as little as a 10-pound difference for those who weren't overweight to begin with), they should notify their doctor. If a patient starts or stops taking a drug that can interfere with the absorption of thyroxine (such as certain antacids, calcium supplements and iron tablets), or if there is a change in the dose of such drugs or medications containing estrogen, that may also impact on thyroxine doses, so any change in such a medication should require a TSH test and dose adjustment of thyroxine. If patients miss doses or take less tablets, their doctor should be informed. If a patient is feeling better and wants to stop thyroxine treatment, the doctor should be consulted before stopping the medicine.

Fun and Fashionable Scar Protection for Post-Thyroidectomy Patients

Bandino was Created by Someone Who Went Through it Herself.

TANYA TOLEDANO

What is a Bandino neckband?

A Bandino neckband is an adjustable band that you can place around your neck to cover the scar from your thyroid surgery. It is available in a variety of fabrics suited to different purposes, including a swimwear fabric that you can wear to protect your scar from excessive sunlight while spending time at the beach or swimming outdoors.

Why Choose Bandino?

As you may already be aware, it is usually recommended to keep your post-thyroidectomy scar covered for the first year following surgery. This is recommended to protect your very sensitive skin as well as to minimize scar visibility in the longer term.

While scarves are a great way to do this, there are certain situations where scarves feel 'a bit much' or are impractical. Keeping your scar covered while swimming also presents its own unique set of challenges. Bandino offers an easy, streamlined solution that is both fun and fashionable. Our SWIM bands can be worn both in and out of the water and are available in a variety of trendy colours. Our EVERYDAY bands are perfect to wear when running errands, while driving on a sunny day and



are also well suited for outdoor exercise. Our ACTIVE collection offers sportier looking bands for your runs, biking, hiking and any other outdoor activity. Finally, our FORMAL collection offers neckbands in classic formal colours and are the perfect solution for outdoor events and celebrations. This collection has received positive feedback from women who want it just for the look and don't even have a scar to cover!

How did Bandino get started?

There is actually an interesting story behind the Bandino brand. Here it is, as told by Founder Tanya Toledano:

(continued on page 20)

Fun and Fashionable Scar Protection (continued from page 19)

I found out that half of my thyroid had to be removed a few months before my husband and I were scheduled to take a 'bucket list' trip to Hawaii which would have been non-refundable since we paid with travel vouchers. My doctor had given me the OK to go, but I was concerned about keeping my scar protected while swimming, walking on the beach and generally being out and about in the sun. I had a few small and large scarves, but 'scarf on the beach' just wasn't me. I needed something small, streamlined and as I put it at the time: 'less *Madame*'.

When I started to go for walks after my surgery, I would cover up with a high-necked jacket. One day, I left the house and while I was walking, realized that my scar was still exposed. I happened to have had a headband on as well as a ponytail holder handy. I decided to slide the headband over my head and around my neck and tighten it using the elastic band. I figured that I might look a little awkward, but at least my scar was protected. When I got home and went into the washroom to wash up, I noticed how it looked in the mirror...and it was NICE! I was certain that this was what I needed. I proceeded to buy a bunch of the headbands in various colours, added some snap closures and had my first collection of neck bands.

These neckbands were perfect for Hawaii – I wore them hiking, swimming, walking on the beach and even out to dinner as sunset was late and I wanted to keep my scar protected in a stylish and streamlined way. They also proved to be perfect for everyday use when I returned back home.

I kept my scar covered for as long as my doctor had advised and I also used the cream that he recommended. I can tell you that today my scar is barely visible. That said, I noticed that if it does get exposed to the sun for prolonged periods, it begins to darken and get more pronounced... so guess what? I continue to wear my Bandino when I go out on the lake, hit the beach or when I know that my neck will be exposed to the sun for longer periods of time.

At the time that I created my bands, I could not believe that such a thing did not already exist and I knew that I had to share my idea with the world.

I decided that I would finally bring this idea to life and thus Bandino was born.

Bandino is proudly made in Montreal, Canada and can be shipped virtually anywhere. From North America to Europe, we have received great feedback about Bandino.

We are continuing to work on new colours, fabrics and styles as we want to make protecting your scar both fun and fashionable.

Finally, it was important to me that this company also help support Thyroid Cancer Research. I have chosen to donate a percentage of the proceeds of the sale of each and every Bandino to the *Head and Neck Department of the Jewish General Hospital in Montreal, Canada*. This is the hospital where I was treated and I will forever be grateful for the care that I received from my Doctor and from the staff there.

Where can I buy Bandino?

Should you be interested in learning more about Bandino, please check us out at: www.mybandino.com

LATS Conference 2023



Delegates at LATS Congress in Curitiba, Brazil, 2023



Ashok Bhaseen, TFI President addressing LATS Congress, 2023

Does thyroid disease change a person?

BOJANA JEDOKSIC
FOUNDER & PRESIDENT OF INNER
WINGS, KRILA U NAMA, SERBIAN PATIENT
ORGANIZATION



This is the translation of an interview published in a Serbian newspaper, *Politika*. The link to the original article is <https://www.politika.rs/scc/clanak/557718/Bolest-stitaste-zlezde-menja-coveka>

Do thyroid issues appear at first glance?

No, but it doesn't mean they don't exist or are insignificant in the majority of cases. Additionally, this does not imply that thyroid illness sufferers are less significant.

Were there more of us here? According to statistics, 10% of the population overall has thyroid illness, and another 10% of people are potential patients who have not yet received a diagnosis.

Hypothyroidism, the most prevalent thyroid disease, can result from a variety of autoimmune disorders or after the gland has been surgically removed.

Therapy is a lifetime. The use of hormone substitute therapy which successfully addresses the issues with regulating metabolism.

Although this may seem simple, the path to a proper diagnosis and therapy can be lonely, difficult, and challenging. All of the signs of hypothyroidism that have been discussed are there, but the ability to act quickly is also crucial.

All the symptoms that are talked about and written about are there, but the important issue is also the willingness to react in time. I noticed the first symptoms when I was in high school, in the form of a change in my neck, weight fluctuations, irregular cycles, chills, and, and a sensitivity to light.

I used the defense strategy of "I see and I don't believe" to avoid acknowledging that, at the age of 18, my health was compromised. Now, if I could turn back time, I would first apologize to my gland for allowing it to suffer and sometimes hurt, when my stubborn head didn't know how to brake.

Fortunately, I experienced a lot of alleviation following the therapy. Then I realized that for years I felt like I was walking uphill with a three-story house on my back, while my friends were moving forward, but without a burden. As time went by, I got better and better.

The time eventually arrived for me to pause, take a step back, and acknowledge that now is the best time

to dedicate myself and my "friend," -the thyroid gland. As time went on, I became aware that I was avoiding mentioning my thyroid condition to keep up with my coworkers, friends, and family. Over time, I discovered what bothered me.

My surroundings and those closest to me did not know what I was facing and how I was living all these years. Then I decided to write them a letter. I wrote to them that someone they care about has a thyroid disease, hypothyroidism, and that it would mean a lot to me if they understood that this gland is the main gland that regulates metabolism and energy for the normal functioning of the body.

The thyroid hormone must be present in the proper concentration for everything to occur in your body and each of your cells. This means that the thyroid hormones must be in the proper balance for us to feel and live well. We need thyroid hormones to think, remember things, stay happy, grow our hair and nails, and have enough energy to go through the day.

Hypothyroidism is a condition in which the thyroid gland does not create enough energy or oxygen, two things that are crucial for all of the body's cells. This is similar to trying to drive a car while being unable to reach the gas pedal.

Recall the time you had the worst flu. Remember how worn out, sore, and exhausted you were after experiencing the worst flu you've ever experienced. Imagine feeling that way every day, but still having to get out of bed, go to work or school, and take care of people as you struggle through the day.

Even though I am happy, upbeat, and in a good mood, know that a lot of work went into it. Because of my puffy cheeks and eyelids, I occasionally find it difficult to identify myself when I look in the mirror. Despite my swelling legs, heavy lead, lack of focus, and "brain fog," I consider myself fearless and I believe I will succeed today.

My loved ones may expect only one thing from me. I want you to look at me and truly ask, "How are you?"

It's a simple yet effective inquiry. When they do, they will know why I need to rest, why I become irritated by sounds and light, why I get chilly even when I shouldn't, and why they shouldn't make fun of me for becoming weary easily while walking along Ada.

For every brand-new day and good morning, I need their support. Their compassion and empathy should be my sources of courage.

Bangladesh Thyroid Society

PROF FARIDUL ALAM, SECRETARY GENERAL BTS
AND VC BUHS



Activities in Last Year

Bangladesh Thyroid Society (BTS) was formally started in 2017 with the aim of improvement of Thyroid Sciences, improvement of knowledge of skill of Thyroid Practitioner and Scientist. This society is also working for the interest of thyroid patients especially for the awareness regarding thyroid disorder. Before formal establishment of BTS nuclear medicine scientist and other branches of medical practitioners are dealing the science. In the last six years Society has been registered by government agency. It has done many scientific and social activity. Bangladesh thyroid society (BTS) has celebrated different days related to thyroid disorders.

It is established that elderly people are more vulnerable to thyroid diseases. Mostly they suffer from subclinical form of hypothyroidism and subclinical hyperthyroidism. These two ailments cause serious consequence in cardio-vascular and neurological diseases. So early diagnosis can save from mortality and morbidity. To do this it is needed to increase knowledge of caregiver as well as general population. In this year Bangladesh thyroid society (BTS) did a seminar on “thyroid disorder in elderly” for physician in auditorium of Institute of Nuclear medicine and allied Sciences (NINMAS), Dhaka Medical College campus, biggest medical college in Bangladesh. This seminar was organized by BTS and NINMAS. Prof Faridul Alam Vice Chancellor of Bangladesh University of Health Sciences and Secretary General of BTS was key note Speaker and Prof Fauzia Molem were the Chair of the session. A good number of experts of panelist discussant were present.



Thyroid seminar on “Thyroid Disorder in Elderly” organized by BTS and NINMAS.

Mother-Baby-Iodine is important project of Thyroid Federation international (TFI). Bangladesh thyroid society (BTS) is partner of the project and implementing among mother and expecting mother. The leaflet and poster were distributed among health care provider and its center. The Importance of Iodine on the Woman and her Baby are well documented by the leaflet and poster of TFI. Bangladesh University of Health sciences celebrated World Thyroid Day focusing mother bay iodine as well as Thyroid-genetics. They made a colorful rally in University of Health Sciences academic and Hospital campus.



Grand rally in University of Health Sciences academic and Hospital campus.



Lady Students are eager about Mother-Baby-Iodine project

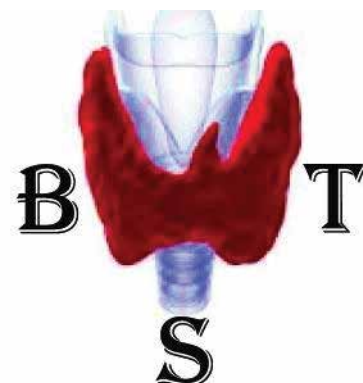
Bangladesh thyroid society (BTS) has celebrated World Thyroid Day in befitting manner, 25th May 2023. They have week long program for spreading the knowledge and awareness throughout the country about thyroid and thyroid week.

Bangladesh Thyroid Society and Bangladesh endocrine society has taken elaborated program throughout the educational institute. Thyroid Society has a rally and press medial conference on 25th May.

A colorful rally was in the campus of Bangabandhu Sheikh Mujib Medical university, held in the morning of 25th May.



Bangladesh organized a seminar on thyroid genetics President of TFI Mr Ashok Bhaseen sends a video message on that occasion.



Thyroid Foundation of Canada

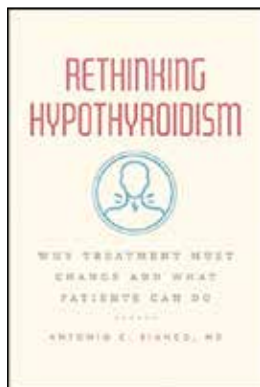
LAZ BOUROS, PRESIDENT

June 2023

This past year our efforts for thyroid awareness, patient support, and thyroid research have been very successful. We have reviewed our achievements in 2022-23 and prepared plans for this coming year.

Two significant news events have occurred in the past few months that bear mentioning:

- The arrival of Dr. Antonio Bianco's groundbreaking new book on Rethinking Hypothyroidism; and



- The approval by Health Canada of Radiofrequency Ablation (RFA) treatment for thyroid nodules. Two RFA facilities have already been established in Toronto.



Dr. Jesse Pasternak, RFA

Awareness/Education

This season, we completed a total of four webinars and published two Thyrobuletin newsletters. We're very thankful to Dr. Jack Wall for his contributions to both Thyrobuletins. Ms. Donna Miniely, past TFC president, delivered a great TFC presentation to A & O Support Services for older adults in Winnipeg.



Dr. Anna Liu Graves' Disease Webinar

Support

Our Help Line Team continues to provide moral support and information on thyroid disease through our toll free 1-800 line, our info emails, and our social media (Facebook, Twitter, Instagram, and LinkedIn).



Thyroid Foundation of Canada

La Fondation canadienne de la Thyroïde

Research

This year, in partnership with the Canadian Society of Endocrinology and Metabolism (CSEM), we awarded a \$50,000 grant to Dr. Ralf Paschke for the second year of his research on the Classification of Thyroid Tumours. We also started a new research section on our website.

Chapter Closings – End of an Era

Sadly, our Ottawa Chapter has formally closed its operations and transferred its financial assets to us. The Kitchener-Waterloo Chapter is planning to close its operations and transfer its assets this summer.

Administration

Katherine Keen continues to do a terrific job providing our day-to-day administrative services and designing and compiling our Thyrobuletin newsletters.

Objectives for 2023-24

Ten objectives were approved by the board for this year.

1. Establish Awareness/Education initiatives for Hypothyroid Patients with Residual Symptoms
This objective was addressed with an educational webinar on the subject given by Dr. Bianco on April 16th. TFC will be promoting the webinar recording of Dr. Bianco within the thyroid community.
2. Establish Awareness initiatives for Combination Therapy with the Canadian Medical Community
We plan to promote the TFC webinar recording of Dr. Bianco with medical associations, obtain support for combination therapy from CSEM, sponsor an educational presentation for family physicians and organize petitions to Health Canada and other medical organizations on this issue.
3. Establish a Minimum of Three Educational Awareness Webinars
Our educational webinars are scheduled for November 2023, February 2024, and April 2024.
4. Establish TFC Medical Advisory Panel / Committee
Creating a TFC Medical Advisory Panel consisting of physicians from diverse areas of the thyroid medical community will expand our medical advisory support. The panel will provide additional resources to help keep our thyroid guides updated and provide more specialized feedback for patient inquiries.

(continued on page 25)

Thyroid Foundation of Canada (continued from page 24)

- Continue to Raise Funds from Pharmaceutical Organizations, Memberships, Individual Donations, Bequests and Light a Tree Campaign

We will continue our fundraising from existing sources and identify new funding opportunities.

- Migrate our TFC Website to a More Secure Platform such as Wix.com

Our current website is now about six years old and is continuously being hacked. Continued website support is becoming costly. One option is to migrate our website to a more secure platform such as wix.com, that would also lower our support costs by including website security.

- Integrate TCC intellectual Property, Financial and Other Assets into TFC

The closing down of Thyroid Cancer Canada operations has been slow. Sarah Eadie and Gillian Vankempen from TCC left the TFC board last year citing legal conflict of interest and lack of time.

- Provide Annual Research Grant for Thyroid Research
We will continue to provide grants for thyroid research through CSEM.

- Update Thyroid Information on our TFC website, Social Media & Publish Thyrobulletin
We will continue to provide updates on thyroid news items monthly, improve TFC's reach to thyroid patients through social media, update educational webinar information and other events, update research articles, publish two Thyrobulletins and deliver Thyroid Presentations to organizations.

- Provide Moral Support for Thyroid Patients
We will continue to support thyroid patients through our toll-free 1-800 line, email and social media.

We are fortunate to have three new board nominees this year! Our Treasurer, Jean-Sebastien Michel will be leaving the board. We thank him for his past support and wish him all the best for the future!

We look forward to an exciting and productive year!

ACTIVITIES AND PROJECTS OF THE NATIONAL ORGANIZATIONS

Croatia

Croatian Association for Thyroid Disease

ROKO GRANIĆ

After the end of the COVID-19 pandemic, the Croatian Association for Thyroid Disease (CATD) continued with its regular activities and reunited with its membership.

In April of 2023, a branch of the Association was established in Slavonski Brod, a city in eastern Croatia, where the members, led by Dr. Fuštar, have already carried out several successful public health campaigns in which they were joined by students of the medical school of the University of Osijek. Their enthusiasm in helping those suffering from thyroid disease and educating the population was almost contagious.

A series of lectures by eminent Croatian experts in the field of thyroidology continued in the Association's headquarters in Zagreb, where they spoke, among other things, about surgical treatment of malignant thyroid diseases, diagnosis and treatment of hyperthyroidism, and the psychological aspect of hyperthyroidism.

Several workshops were also held in the premises of the Association in Zagreb, where CATD activists made decorative items that will be sold as part of the celebration of World Thyroid Day in May.



Our president's walk from Zagreb to Petrinja

May 25th – World Thyroid Day – is traditionally marked in the center of Zagreb with a public health campaign to raise awareness about thyroid diseases. The celebration was attended by many citizens, members of the Association as well as friends of the Association – doctors from several Zagreb hospitals who sold t-shirts with the image of a butterfly, decorative ribbons and objects as well as pink peonies – the patron flower of the Croatian Association for Thyroid Diseases.

In May, the president of the Association, Mrs. Verica Mešić, accompanied by several other enthusiasts, walked about 60 kilometers between Zagreb and Petrinja – a

(continued on page 26)

Croatia (continued from page 25)

city that suffered heavily in the Homeland War and was destroyed again in the recent great earthquake. All the money collected during this campaign was donated to the renovation of the hospital's laboratory in Petrinja.

In July 2023, a traditional CATD race was held in Zagreb's Maksimir Park with the participation of members of the local athletics club. This action was aimed at promoting exercise as a necessary element of overall health, including thyroid health. Race participants



Marking World Thyroid Day in Zagreb.

were given T-shirts with the image of a butterfly and CATD insignia and were offered refreshments.

It didn't matter who won because the most important thing was to participate, socialize and donate your time and goodwill to those in need.



Establishing our branch in Slavinski brod.



Traditional CATD race in Maksimir Park.

ACTIVITIES AND PROJECTS OF THE NATIONAL ORGANIZATIONS

Ghana

Thyroid Ghana Foundation (TGF)

The Thyroid Ghana Foundation (TGF), since its inception on 13th July 2018, has been engaged in awareness creation of thyroid disorders, supporting thyroid patients, and encouraging thyroid research. The Foundation embarks on advocacy programs which aims at addressing several thyroid health related issues at the policy and institutional levels and facilitates closer working relations between departments involved in thyroid disease management, treatment, and research.

The Foundation has also worked closely with the following Departments: Nutrition and Dietetics, and Center for Radiography and Nuclear Medicine within the country. The TGF also seeks to engage government agencies such as Ministry of Health, Ghana Standards Authority, and the Ghana Food and Drugs Authority to introduce policies toward promoting thyroid health. More critically, the Foundation aims to ensure that most thyroid drugs are covered and supplied under Ghana's National Health Insurance Scheme. The TGF, since its launch, has organised various programs and campaigns on thyroid awareness in the country and beyond, using mediums such as webinars, health talks and walks, and

regular engagements with thyroid patients and the media. The work of the foundation is managed by volunteers who readily avail themselves to support its activities.

Past and Present Activities

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

The TGF has reached an agreement with three medical laboratory and imaging companies (MDS-Lancet Laboratory, Metropolis Healthcare and Scanport Laboratory) and currently offers discounts on all blood tests and imaging investigations for members of the

(continued on page 27)

Ghana (continued from page 26)

Foundation. The TGF organises patient forums regularly, which gives patients the opportunity to seek clarity about their condition.

The TGF in collaboration with the University of Ghana Medical Centre (UGMC) during the 2021 World Thyroid Day started performing thyroid surgeries for needy thyroid patients at a subsidized fee. So far, 28 surgeries have been done successfully.

The Foundation also held an event in collaboration with Akoma-H Productions themed “Ghana Health Awards and Honours Media Launch” at the University of Ghana Medical Centre on 30th November 2022. The event, aimed at recognizing and awarding deserving healthcare providers, personnel, and facilities as well as to raise funds for needy thyroid patients, was chaired by Dr. Darius Osei, C.E.O of UGMC.

The president/founder of the TGF, Nana Adwoa Konadu Dsane (Mrs), also, received an award on 10th March 2023 as the African Outstanding Woman in Health organised by the African Outstanding Women Awards, ASKOF Productions Limited in Abidjan.



Winner of Africa Outstanding Women in Health Award for 2023

Media Campaigns



The TGF continues to be active within the media space to increase awareness on thyroid, its health, and related issues. The Foundation has been hosted by TV-Africa during their breakfast live show on 23rd May 2023, Metro TV during their Morning Rush show on 24th May

2023, and Original TV during their ‘Adwene pa’ show on 24th May 2023.

5Th Anniversary Celebrations and International Thyroid Awareness Week

The TGF and UGMC in collaboration with the Thyroid Federation International celebrated the 15th International Thyroid Awareness Week with a series of week-long activities. On World Thyroid Day, 25th May 2023, a forum was held in the Auditorium of UGMC and was themed:



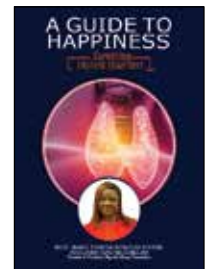
“THYROID AND GENETICS”. The event was chaired by Dr. Darius Osei, CEO of UGMC.

The president of Thyroid Federation International, Ashok Bhaseen from Canada and Irouma Ofortube from Thyroid Awareness and Support Initiative (TASI), Lagos, Nigeria were hosted.

The speaker at the webinar was Dr. Solomon Brookman, a Consultant General Surgeon, and Head of Surgical Department at UGMC, who spoke about the pathophysiology of thyroid conditions. Key notes speakers were given by Ashok Bhaseen and Irouma Ofortube. Notable guests included Rev. Prof. P. F. Ayeh-Kumi – Board Chairman of TGF, the Management of UGMC, Dr. Josephine Akpalu, Head of Endocrine Department, Korle-Bu Teaching Hospital (KBTH), Academics, medical practitioners, staff of UGMC, thyroid patients, beneficiaries of the subsidized thyroid surgeries, volunteers of TGF, and some members of the public. Also, Media personnel from Daily Guide Network, Hello-Gh (hello-gh.com), newsroom Metro TV, Peace FM, Angel TV/FM, and Radio Universe had coverage of the event.

To mark the celebration of the 2023 World Thyroid Day, the Thyroid Ghana Foundation launched the Thyroid Ghana Foundation Patients’ Support Fund. During the event, the Founder & President of TGF Nana Adwoa Konadu Dsane (Mrs.) mentioned in her speech how inspiring and beautiful the journey has been despite the challenges faced. She expressed gratitude to everyone who supported in diverse ways for the successes attained over the years.

A book, written by the Founder & President, titled: “A GUIDE TO HAPPINESS – Surviving Thyroid Disorders” was launched during the event by Prof. Aaron Lawson, Director of Medical Training and Simulation of UGMC and Mr. Kafui Dey, Renowned Media person in Ghana.



Another presentation for the day was on appropriate diet for thyroid health and disorders; this was presented by RD. LD. Frank Ayimadu – Registered Dietician, who illustrated and emphasized the uses and benefits of appropriate herbs and spices to keep the body healthy.

The Foundation presented Citations to twelve (12) individuals for their support to the Foundation over the years.



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

ANNA MARIA BIANCIFIORI, PRESIDENT CAPE ITALY

GIULIA GIOMBOLINI, SECRETARY CAPE ITALY

Some of our Activities

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, and Liguria with Ape la Spezia.

There are several events that each association organizes in its own territory; Here are some past events;

- * Conference entitled “Novelties in the Diagnosis and Therapy of some Thyroid and Oncological Diseases” organized by La Lumaca odv in Perugia, during which the representatives of C.A.P.E. of two associations (Aibat Parma and Ameir Irpinia) took part. During this conference, which lasted two days, several distinguished specialists took part, including: Dr. Pier Giuseppe Pelicci, scientific co-director of the European Institute of Oncology (IEO, Milan, Italy) and chairman of the Department of Experimental Oncology (DEO), Prof. Laura Locati, manager and researcher at the IRCCS National Cancer Institute Foundation, Prof. Silvia Morbelli, associate professor of nuclear medicine at the University of Genoa and many others.



From left: Anna Maria Biancifiori president of C.A.P.E. and of the La Lumaca odv Association, Emma Bernini president of Aibat Parma, Antonella Grillo Vice-president Ameir Irpinia, Giulia Giombolini secretariat C.A.P.E., Sara Giombolini treasury C.A.P.E.



- Health prevention and thyroid ultrasounds, in various areas of the territory as well as in schools: during these days the associations go to schools and hold small conferences. In addition, free thyroid ultrasounds for children, as well as implementing iodophylaxis awareness campaigns.



- Solidarity projects such as “a Doll with a Big Heart” (Aibat Parma association), a series of charity events aimed at making dolls in support of the association.



AMeCAT Mexico

CLAUDIA FIGUEROA , PRESIDENT AND FOUNDER

AMeCAT A.C. is a nonprofit association created in 2015 by patients diagnosed with thyroid cancer, made up of an executive committee, a medical Advisory Committee, and a group of patients and volunteers committed to the cause.

We carry out actions to raise awareness of Thyroid Cancer and diseases of the gland, aimed at the general public, doctors and health professionals, through awareness and education on the main warning signs and symptoms. We carry out informational medical days for timely detection and early treatment of thyroid cancer, providing guidance, emotional and psychological support to the patient and their relatives, and emphasizing the importance of multidisciplinary care for a better quality of life. We hold monthly integration activities “Café Tiroides” for patients and relatives affected by this diagnosis.



Founding Committee.



8th Anniversary.



8th Anniversary with patients.

AMeCAT has carried out public policy advocacy activities presenting initiatives in forums and activities presenting initiatives in 2019 and 2020 respectively, all with the aim of reducing the impact on the population and improving the quality of care for patients diagnosed with thyroid cancer in Mexico.

We provide guidance and comprehensive support to patients with thyroid cancer through treatment and referral to specialist doctors for second opinions.

AMeCAT has more than 3,500 affiliates and is present in the main states of the Mexican Republic and carries out activities in conjunction with organizations and patient groups in Europe, the United States and Latin America (Colombia, Peru, Argentina, Chile).

WEB: WWW.AMECATMEXICO.ORG

INSTAGRAM: [HTTPS://WWW.INSTAGRAM.COM/AMECATOFICIAL/](https://WWW.INSTAGRAM.COM/AMECATOFICIAL/)

FACEBOOK: [HTTPS://WWW.FACEBOOK.COM/AMECATOFICIAL](https://WWW.FACEBOOK.COM/AMECATOFICIAL)

LINKEDIN: AMECAT



Thyroid Awareness and Support Initiative

IRUOMA OFORTUBE, EXECUTIVE DIRECTOR,
THYROID AWARENESS AND SUPPORT INITIATIVE (TASI)

TASI is a non- profit and non- Governmental Organisation, registered and based in Nigeria, West Africa. TASI is a member country representing Nigeria in Thyroid Federation international (TFI). 2023 has been a very eventful year, characterised with many activities. We have been in into the advocacy for thyroid health awareness and support for people affected with thyroid disease since 2018, our advocacy is spread across Nigeria in both rural and urban communities in Nigeria.

We started the year with media awareness tour covering five radio stations and four Television stations spreading and escalating the awareness of thyroid disease while harvesting patients in both rural and urban areas in Nigeria where thyroid disorders are found more prevalent.



With the overwhelming population of patients recorded seeking for support, the collaboration of more healthcare and medical personnel was sought in different regions of the country to provide medical and other therapeutic support for the patients diagnosed with thyroid disease. Most of them have been down with different kinds of thyroid disorders with goiter which is more common. While few have their resources but confused on the right direction to take in quest for solutions to their problems, a larger percentage are indigents who neither have the funds nor have access to proper healthcare. Our advocacy on the elimination

of harsh societal superstitions and stigma on people suffering from thyroid disorders is gradually bearing fruits because some community leaders who use to mastermind the societal stigma are becoming the key gate keepers of thyroid awareness advocacy. In the light of that, many people suffer from thyroid disorders are more confident of their survival and as a result coming out to face their fears, to get proper diagnosis and to seek the right medical support without any fear of death or societal stigma.

On that note we launched our “Adopt A Patient Scheme”. This is another concept and strategy initiated by TASI to solicit for more support from charitable individuals, philanthropists, partners to adopt patients, could be individual or collectively sponsor patient’s medical/surgical intervention where necessary. This was necessitated by the overwhelming influx of patients and the rising rate of thyroid disease in Nigeria.



Ashok Bhaseen, TFI president, and Iruoma Afortube, Executive Director TASI, at the ITAW 2023 event in Ghana.

(continued on page 31)

TASI (continued from page 30)

TASI commemorated the International Thyroid Awareness Week (ITAW) 2023 and World Thyroid Day 2023 (Thyroid and Genetics) in a phenomenal way with a well-attended public lecture, with senior Consultant Endocrinologist as the Keynote Speaker among others and a good will message by The Thyroid Federation International TFI, Mr Ashok Bhaseen added spice to the program. A grand event that had four brilliant speakers and about 200 guests which includes, thyroid patients, survivors, medical and healthcare officials, community leaders, corporate organizations, Government agencies.

The highest point was the visit of the TFI President in Africa, Ghana precisely. It was a journey to Africa that was meant to start from Nigeria and end in Ghana but due to Visa terms and conditions he could not secure Nigerian visa and the itinerary truncated. Unreserved Gratitude to the TFI Board of Trustees for funding an air ticket for TASI representative in the person of Iruoma Ofortube, the Founder/President of TASI to join the TFI President and Ghana Thyroid Foundation to celebrate the World Thyroid Day on the 25th of May with a pleasant hospitality by Ghana Thyroid Foundation. This phenomenal decision and unprecedented step taken by TFI is a huge encouragement to African Thyroid Advocates which will bring a boost to African Thyroid Organisations and strengthen the advocacy in Africa while projecting it to more global pedestal, for greater impact in Africa at large.

Part of the events mapped out in TASI to commemorate 2023 ITAW was our biennial TASI Free Medical/Surgical Outreach which comes up every 2 years. This is an opportunity provide surgical intervention to the indigent patients harvested during our awareness in different rural communities who cannot afford the huge hospital bill. The free Medical/Surgical Outreach 2023 was held from the 6th -15th of June 2023. The funding was made possible from our "Adopt A Patient Scheme" Donations and more collaborations with a team of Medical/Surgical consultants who also added their support by subsidizing their professional fees, this is a strategy we are leveraging now to make impact consistently supporting patients while we seek more International support, partnership and sponsorships. With the paucity of funds and massive efforts, The Surgical outreach ended successfully with 40 successful surgeries without any recorded casualties or complications, we could not attend to all patients registered for the surgical outreach, numbering about 78, due to limited funds. These 40 latest surgery



survivors makes it 180 beneficiaries of both subsidized and free surgery since 2019. The entire programs in commemoration of the International Thyroid Awareness Week, the entire program was concluded on the 16th of June in TASI with a press conference, and media chat at the hospital venue, as it is imperative to draw the attention of the relevant, on the need for aggressive advocacy on thyroid health while communicating and exposing the plight of people suffering from thyroid diseases.

2023 ITAW and WTD remains the most memorable so far. TASI is open to collaborations, sponsorships, partnership and funding both locally and internationally to achieve our organizational goals and make more impact in the Sub-Saharan Africa.

Contact TASI: tasinigeria@gmail.com

Facebook Page: Thyroid Awareness and Support Initiative (TASI)

Instagram: [@thyroid_awarenessnigeria](#)

Twitter: [@fighthyroidism](#)



Goldheart Thyroid Awareness Foundation

FLORENCE OKETONA, CEO AND FOUNDER,
GOLDHEART THYROID AWARENESS FOUNDATION

Our foundation is registered in Nigeria under the companies and Allied Matters Act. We are saddled with the responsibility of creating awareness about thyroid health, function and malfunction. Over the years our foundation has succeeded in changing the mindset of people in our immediate and surrounding communities about the thyroid health. Prior to this time, there have been myths surrounding the thyroid disease, it was mostly perceived as a spiritual affliction as most of the symptoms are left undiagnosed. Our foundation has sensitized a number of people through our public outreaches, radio programs community outreaches, public lectures and most especially on our social media pages. Our social media page has a wide reach and gets wider and wider due to sponsored ads, constant posts and excerpts talking about the thyroid health.

The symptoms of thyroid disease were subjects which were hardly discussed because most people felt ashamed to talk about it for fear of being taken to spiritual homes for deliverance from evil spirits which are usually gruesome and painful to the victims. As a result of this, a number of people have died through to this ignorance and misconception.



Florence Oketona, CEO and Founder of Goldheart Thyroid Awareness Foundation.



Our awareness creation has reached a wide range of people as we receive calls from people who got to know about the thyroid disease through our social media pages and our constant radio programs.

During this year's Thyroid Awareness week, May 2023, we reached out to a community of women and conducted free thyroid function tests with support from our donors and our supporting hospital Hope Haven Hospital Jos. This was a much-needed outreach as most people tested do not have the necessary finance to carry out the test which is a bit costly.

In a nutshell, our foundation having gone through a difficult time during the covid and an economic shortfall in our country, was able to use our out-of-pocket funds to continue to fund the foundation.

Goldheart Thyroid Awareness foundation is looking forward to getting more supports to enable us create more awareness in our part of the country which is the Northern part of Nigeria. The level of awareness in this axis of the country is relatively low.

www.goldheartthyroid.com

Facebook: Goldheart Thyroid Awareness Foundation

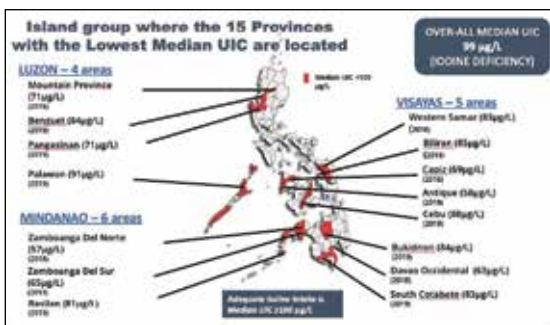
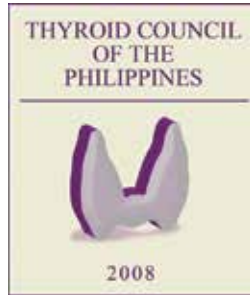
Instagram: goldheartthyroid



Thyromobile Philippines Project

DR. TEOFILO O.L. SAN LUIS,
PRESIDENT, THYROID COUNCIL OF
THE PHILIPPINES

The Thyromobile Philippines Project seeks to enhance thyroid health information and diagnostic care delivery to vulnerable segments of the population, especially to the pregnant & lactating women (PLW).



Targeted are 15 provinces with high prevalence of Iodine Deficiency Disorders (IDD) all over the country to increase awareness on the importance of iodine in brain development of the child in its first 1,000 days of life.

The Thyromobile distributes TFI's MotherBabyIodine infographics to hundreds of participants attending each of the Capacity-Building seminars for health care professionals and lay forum for women of reproductive age where thyroid screening & testing take place.

Thyroid assessment includes neck palpation & clinical evaluation, blood TSH & FT4, urinary iodine concentration (UIC), portable thyroid ultrasound, and quantitative iodine levels in household salt using WYD technology.



Thyromobile: What is it?

The Thyromobile is a vehicle carrying needed equipment and manpower to deliver public information and thyroid health services to targeted communities.



The thyroid health delivery consists of diagnostic and therapeutic services and provides educational insights to pregnant and lactating women (PLW) on the deleterious effects of Iodine Deficiency Disorders (IDD) on the course of their pregnancy and on the brain development of the children they are bearing.

Why is it important to send the Thyromobile to communities?

Data from official surveys of DOST-FNRI still show high prevalence of Iodine Deficiency Disorders (IDD) among PLW in 15 provinces of the Philippines. They stand to benefit from diagnostic testing right in their localities without the need to travel to health centers which may not even have facilities for pertinent thyroidal testing based on clinical assessments.

Public awareness of IDD is enhanced even more when targeted communities are visited upon coordination with local government units (LGUs) or non-governmental organizations (NGOs) and broadcasted through traditional or social media.

What happens during the Thyromobile visit?

The visit of the Thyromobile into the locality will feature conducting seminars for health care professionals and allied workers (provincial/ municipal levels) on the early recognition of thyroidal illnesses based on clinical manifestations and physical examination. There will be lay forums organized by local government units (LGU), medical



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Thyromobile Philippines Project (continued from page 33)

societies, civic and professional associations, or other advocacy organizations targeting women of reproductive age (WRA), especially focusing on PLWs. In these lay forums, there will be:

1. Screening of WRA / PLW for thyroid problems in the municipality or village
2. Collection of biological specimens (blood for TSH and FT4 and urine for urinary iodine concentration)
3. Thyroid ultrasound of patients with palpable nodules
4. Quantitative testing of household salt for its iodine content

Lastly, the women (and men) who have goiters which can no longer be treated medically but ought to be handled surgically (or through other ways) may be referred to Provincial / District Hospitals for definitive surgery (thyroidectomy).



Who are the proponents of the Thyromobile?

The Thyromobile is a collaborative undertaking of the following:

1. Iodine Global Network Philippines (IGNP) which shall provide the program implementation guidelines in the conduct of the project. IGNP will coordinate with local medical associations, doctors, nurses, and other health care professionals in mobilizing their support for the events in identified areas, in tandem with governmental agencies.
2. Rotary Club of University District Manila (RCUDM) which shall procure sponsorship funding with Rotary International through its Global Grant for the Thyromobile project for implementation in the Philippines to cover the equipment, logistical and program requirements.
3. Salinas Foods, Inc. (SFI) which shall support the Thyromobile program implementation through coordination with local government units (LGUs), especially their health offices (provincial, city and



municipal) and providing for venue, food, and invitation of program attendees; making available WYD Iodine Checker testing kits during the events; sponsoring the supply of iodized salt to all activity participants free of charge; and in providing manpower for the conduct of the Thyromobile as it moves from provinces to provinces as designated to be visited.

4. Philippine Thyroid Association (PTA) which shall provide resource speakers in the educational programs of the Thyromobile project during the lay forum and conduct capacity-building for health professionals.
5. Thyroid Federation International (TFI), a worldwide patient organization, which shall disseminate information on its MotherBabyIodine (MBI) initiative in its network and provide instructional materials for attendees on the value of iodine in human health and optimal nutrition.
6. Merck & Company, a pharmaceutical company, which will provide support to the operationalization of Thyromobile through its grants for the point-of-care testing of thyroid function (TSH and FT4).

Which areas are targeted to be visited by the Thyromobile?

The Thyromobile will prioritize its visit to the 15 provinces with high prevalence of IDD (see map). Thereafter, it will move around the country as per arrangements with concerned Provincial Governments or with relevant medical specialty societies to study local situations more in detail and adopt measures to alleviate IDD.



The Swedish Thyroid Association (Sköldkörtelförbundet)

Highlights of 2022-2023

About Us

The Swedish Thyroid Association is a non-profit organisation for people living with thyroid disease in Sweden and their relatives and loved ones. The organisation was founded in 1993 and became a national association in 2017. Our main focus is to achieve the best possible healthcare for half a million Swedish thyroid patients and for every patient's right to individually tailored care, in accordance with the Swedish Patient Act. At the end of 2022 we had 6,000 members with local organisations in 11 counties nationwide.



Our main objectives are:

- Thyroid care should be based on current knowledge.
- People with thyroid disease should have the right to individualised treatment.
- People with thyroid disease should have equal opportunity for specialist care (to meet an endocrinologist specialising in thyroid disease).
- The establishment of clinical research and competence centers (thyroid clinics) for all thyroid-related problems.
- Increased research in the thyroid area.
- Development of national guidelines and a national quality registry for thyroid disease.

Summary of Recent Activities and Achievements

Great impact for patients' input in Sweden's first national guideline for thyroid disease.

In January 2023 the first national guideline for thyroid disease was launched by the National system for knowledge-driven management within Swedish healthcare. A national working group led by Helena Filipsson Nyström, associate professor of endocrinology and senior physician at Sahlgrenska University Hospital, developed the national guideline for hyperthyroidism (overactive thyroid gland). The working group consisted of endocrinologists, surgeons, nurses, patient representatives and other experts. There is a lot that is good about this guideline. For example, it recommends that patients with hyperthyroidism have access to a

contact nurse, which is standard in many other diseases. "And that there should be more focus on follow-up and rehabilitation", says Katarina Nydahl, medical expert at the Swedish Thyroid Association. In 13 sections of the guideline, the patient's perspective has been highlighted (blue box that begins with the text "From a patient's perspective"), which we see as a strength and something that other guidelines should follow.

Seminar about Thyroid Disease at the Swedish Parliament

On June 15, 2023 the Swedish Thyroid Association was invited to speak at a seminar at the Swedish Parliament entitled "What is required to improve the management of patients with thyroid disease?"

About half a million people in Sweden live with thyroid disease. In 2023, a Swedish national guideline for hyperthyroidism was published (overactive thyroid gland), however, there is still no national guideline for the much larger group of thyroid patients living with hypothyroidism (underactive thyroid gland). The lack of a guideline contributes, among other things, to unacceptable differences in diagnosis, treatment and follow-up of patients with hypothyroidism in Sweden.

Up to twenty percent of patients state in surveys and in research studies that they have persistent symptoms despite treatment – how can politics guide the care system so that these patients can have an increased quality of life and live a healthy life despite their illness? Anna Bergkvist, president of the Thyroid Association, Katarina Nydahl, operations manager and medical expert at the Swedish Thyroid Association, and Helena Filipsson Nyström, associate professor of endocrinology and senior physician at Sahlgrenska University Hospital, who has led the national effort to develop the national guideline for hyperthyroidism, took part in the conversation.

What are the challenges?

- There are no national guidelines and care programs for hypothyroidism – this leads to unequal care, lack of knowledge and the disease not being taken seriously.
- Major deficiencies in the follow-up of care.
- We know too little about the care of hypothyroid patients, and what we know doesn't reach patients and caregivers.

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Sweden (continued from page 35)

What can members of the Swedish Parliament do?

- Give the National Board of Health and Welfare the task of developing national guidelines for hypothyroidism.
- Add targeted funds for hypothyroidism research.
- Add thyroid disease to the list of diagnoses when investing in women's diseases.

Films about thyroid disease

With the aim of raising awareness about thyroid disease, five short films were launched during International Thyroid Awareness Week in May 2023. The first two films give general information about the thyroid, including common symptoms of hyper- and hypothyroidism. The third film gives 5 tips for people living with thyroid disease. The last two films are about thyroid cancer and precision medicine. The films were produced by the Swedish Thyroid Association with support from Orifarm and Roche. All five films can be viewed on Sköldkörtelförbundets YouTube channel (<https://www.youtube.com/@Skoldkortelforbundet>).



The Board of the Swedish Thyroid Association, from left: Anna Bergkvist (chair), Christina Medin, Pernilla Tofft, Ellinor Vestman, Åsa Moe, Marie Skuggvik, Birgitta Kihlberg, Christina (Tina) Fernerud Björklund and Katarina Nydahl, PhD (operations manager and medical expert). Not included in the picture: Marie Karlsson (financial manager).

TFI attending Conferences



Ashok Bhaseen with TNT President, Dr Roberto Valcavi, at the 2nd International. TNT meeting, Reggio Emilia, Italy



Ashok Bhaseen with Prof. Martin Schlumberger at the WCTC in London, June 2023.



Ashok Bhaseen with ITC 2025 Congress Chair Ana Luiza Maia, at LATS in Brazil, April 2023.

The Thyroid Trust



The Thyroid Trust is a UK registered thyroid charity which was set up in 2019. We are led by patients but work closely with medical professionals and researchers. We provide reliable information and peer support to our thyroid patient community.

We run regular online and face to face peer support and information events. At our events, we talk about all things thyroid and listen to endocrinologists and other health experts share their knowledge with us. We also have patients sharing their journeys, tips, advice and supporting each other. The brand identity for The Thyroid Trust represents a diverse, open support circle where everyone is welcome. Our colour scheme reflects our values of openness, learning, transparency, professionalism and caring.

In the four years we have actively been involved in influencing change, from promoting clinical trial availability, promoting patient involvement in research, engaging members of British parliament, input in NHS primary care changes and working together with other thyroid partners. We have published two major reports into access issues with liothyronine (T3) and were successful in persuading NHS England to revise their prescribing guidance for this treatment.

During the past 6 months we have hosted online talks by Professor Karol Sikora, Antonio Bianco MD PhD, Professor Margaret Rayman and are looking forward to hosting Professor Simon Pearce, Professor Kirsten Boelaert and Professor Lakdasa Premawardhana later this year.

For this year's International Thyroid Awareness week, we ran a #thyroidfamily campaign. We had patients sharing their family experiences of thyroid disorders, a fundraising campaign where some of our community members ran half marathons, held tea parties, made paper butterflies, had a thyroid day at the beach and shared all our awareness posts across our social networks.



We recorded a special charity hour radio interview about Graves' disease on UK health Radio and worked in partnership with the Fahmidan Journal to produce a thyroid warrior special in which poems and other literary works were submitted and published.

To continue our efforts in raising the profile of thyroid health we also have a monthly 'Talk Thyroid' column in UK online publication 'Health Triangle'.

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

www.thyroidtrust.org

Twitter: @ThyroidTrust

Instagram: thyroidtrust

Facebook: The Thyroid Trust

Linkedin: The Thyroid Trust



May 25 to 31, 2024
**14th International
 Thyroid Awareness Week**
www.thyroidweek.org

Graves' Disease & Thyroid Foundation: Bringing Patients and Caregivers Together over ZOOM.

KIMBERLY DORRIS, GDATF EXECUTIVE DIRECTOR

There have been many advances in technology since the founding of the Graves' Disease & Thyroid Foundation (GDATF). In the early 1990s, GDATF Founder & Chair Emeritus Nancy Hord Patterson, Ph.D. used to respond personally to sacks full of snail mail stored in her living room! The Foundation has made adjustments to our patient education and support initiatives as major technological shifts occurred, including email, the Internet, and mobile phones. However, perhaps the most profound shift in recent years has been the ability to bring patients and caregivers together quickly and inexpensively via videoconferencing tools. The GDATF hosted our first ZOOM support group meetings in 2020, and we currently offer two meetings per month. Meeting by meeting, we've made adjustments based on attendee feedback as well as trial and error using this new technology. Key aspects of our program are noted below, and might help other patient organizations get started with online support groups. (Of course, modifications might be needed based on the number of time zones in the country, internet connectivity, and other factors.)

Initially, only one meeting per month was offered, but as interest has expanded, we are currently offering two, and we have the flexibility to expand further based on demand.

The process starts with a support group email list, which is separate from our regular email list. We maintain a running list of patients and caregivers who have specifically requested information about support groups. Attendees must register in advance to participate on a specific day/time, and registration links are typically provided only to this list. This is to prevent meetings from being infiltrated by spammers or companies with products to sell. Our intent is to provide a safe space for attendees to share their most personal experiences and to receive credible information. We are currently using Vertical Response to maintain our email lists. (A future goal is to maintain this in our own Customer Relations Management software, but we have yet to troubleshoot these emails getting caught in spam filters.)

Meeting dates are determined by allowing the members of the email list to vote each month. We've repeatedly asked if attendees would prefer to have meetings on a set day/time of the month, but our community members seem to like the flexibility of voting

each month. We typically offer four different dates, which are a combination of weekday afternoons, weekday evenings, and Saturday mornings, and select the two dates that will allow the largest number of respondents to participate. When we were only offering one meeting per month, we used Doodle Polls, but that does not accommodate selecting two meeting dates, so we are currently using Google Forms.

We initially took advance registrations using Eventbrite, but we are currently using Zoom. Both platforms have advantages and disadvantages. Eventbrite has excellent waitlist functionality if the meetings fill up, but Zoom has none – if the meeting is full, Zoom shows a notice that “Registration is Closed”. (We cut off registrations at 12 attendees in order to ensure that everyone has a chance to speak.) Eventbrite has great functionality for communicating with registered attendees prior to the meeting – for example, to remind registrants to cancel if they are unable to attend. Zoom has very limited functionality for communication, although you can download a list of registered attendees and send an email outside of ZOOM. The advantages of ZOOM are easier use of meeting templates so that you don't have to reinvent the wheel each month, the ability for registrants to add the meeting to their calendar with a simple click, and the ability to pre-screen registrants based on their answers to registration questions. When we polled members about which option they preferred, over half had no preference, 38% preferred ZOOM, and a small remainder preferred EventBrite.

For the registration questions, we collect a minimum of information to make the process easy: full name and email address. We also have a number of optional questions, including name pronunciation, nickname (if different from registered name), and requested topics for discussion. Finally, all attendees must agree to abide by the GDATF's meeting rules, which do not allow discussion of unproven, so-called “alternative” therapies. The GDATF is committed to providing our community members with credible, evidence-based information, and a meeting can go sideways quickly if attendees come in with different expectations as to what can be discussed. While we do often discuss nutrition, exercise, and stress management, these are addressed in the context of self-care and not as a “cure” for Graves' disease or thyroid eye disease.

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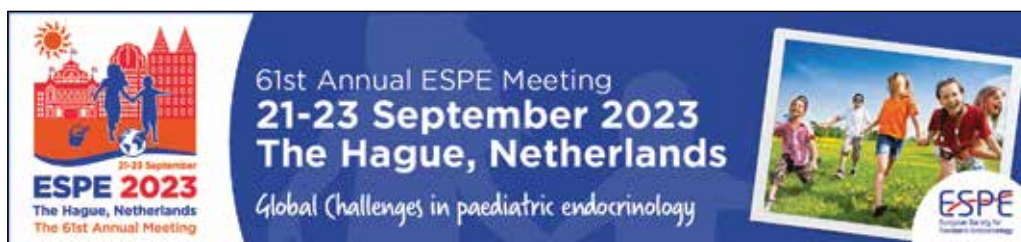
USA (continued from page 38)

Prior to the meeting, we review the list of topics and compile them into a single list. We also do a couple of poll questions with each meeting, typically related to the topics that were of interest to the group. Meetings are hosted by me, Nancy, and our patient advocate, Ellen Brightly. I log on 15 minutes early so that those who are new can join before the meeting starts to sort out any technical issues.

The meeting begins with everyone doing a quick introduction (name, when they were diagnosed, and which treatment option they selected). If the meeting is full, it's important to keep an eye on the clock in case one attendee takes a lot of time with the introduction. Some people are grateful to have a forum where people understand what they are going through and can lose track of time during their introduction – but it's important to ensure equal time for everyone to speak. If an attendee needs a lot of extra attention, facilitators can offer to follow up with them outside the meeting. Once introductions are complete, we work through the list of requested topics and then conclude with an open discussion. We work to ensure that all of the requested topics are addressed, although sometimes they are taken out of order, depending on how the discussion is flowing.

Our meetings are scheduled for one hour, but facilitators are available to stay later if any attendees have additional questions. (Note: the GDATF has a paid subscription to ZOOM, but a meeting could still be hosted with a free subscription, although the meeting time would need to be cut to 40 minutes.)

We're always working to make the meetings better and to troubleshoot problems (one major issue is people who register and then don't show up, despite repeated reminders). We are also looking to host some meetings that have a narrower topic of focus – for example, patients who have had a thyroidectomy. Overall, ZOOM support groups have been a valuable addition to our patient offerings, allowing us to bring together patients and caregivers from all over the USA. (And we sometimes have international attendees as well!) Please feel free to reach out to the GDATF at info@gdatf.org if you have questions about starting your own online support program!



TFI Member Organizations

AUSTRALIA

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

BANGLADESH

Bangladesh Thyroid Association (BTS)
www.buhs.ac.bd

BELGIUM

Leven Zonder Schildklier
www.levenzonderschildklier.be

BRAZIL

Instituto da Tiróide
www.indatir.org.br

BULGARIA

VIOM
www.thyroidbg.com

CANADA

*Thyroid Foundation of Canada /
La Fondation canadienne de la Thyroïde*
<https://thyroid.ca/>

COLOMBIA

*Asociación colombiana de pacientes de
cáncer de tiroides*
www.acolcat.com

CROATIA

Croatian Association for Thyroid Disease
tfi@thyroid-fed.org

DENMARK

Stofskifteforeningen
stofskifteforeningen.dk

FINLAND

Suomen Kilpirauhasliitto ry
<https://kilpirauhasliitto.fi/>

FRANCE

Association Vivre sans Thyroïde
www.forum-thyroïde.net

GEORGIA (EU)

*Georgian Union of Diabetes and
Endocrine Associations*
diabet@access.sanet.ge

GERMANY

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

Schilddrüsen-Liga Deutschland e.V.
<https://www.schilddruesenliga.de/>

GHANA

Thyroid Ghana Foundation
<https://thyroidghanafoundation.org/>

GLOBAL

MCT8-AHDS Foundation
<https://mct8.info/>

GREECE

Hellenic Thyroid Patients Organization
greece@thyroid-fed.org

INDIA

Thyroid Federation of India
india@thyroid-fed.org

*South Asian Federation of Endocrine
Societies*
www.safes-endocrine.com

IRELAND

Thyroid Support Ireland
[https://www.facebook.com/
ThyroidIreland/](https://www.facebook.com/ThyroidIreland/)

ITALY

*CAPE –Comitato delle Associazioni dei
Pazienti Endocrini*
www.capeitalia.org

JAPAN

Dr Fumito Akasu (Contact)
www.tfj.jp

KENYA

*Thyroid Disease Awareness Kenya
Foundation*
[www.facebook.com/
thyroiddiseaseawarenesskenya](https://www.facebook.com/thyroiddiseaseawarenesskenya)

MEXICO

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

NEPAL

Thyroid Foundation of Nepal
nepal@thyroid-fed.org

THE NETHERLANDS

Schildklier Organisaties Nederland
www.schildklier.nl

NIGERIA

*Goldheart Thyroid Awareness
Foundation*

Facebook: Goldheart Thyroid
Awareness Foundation

*Thyroidism Awareness and Support
Initiative*

Facebook: Thyroidism Awareness and
Support Initiative

NORWAY

Stoffskifteforbundet
www.stoffskifte.org

PAKISTAN

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

THE PHILIPPINES

Thyroid Council of the Philippines
philippines@thyroid-fed.org

PORTUGAL

Associação das Doenças da Tiróide
www.adti.pt

RUSSIA

Thyroid Foundation of St. Petersburg
russia@thyroid-fed.org

SERBIA

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

SOUTH KOREA

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

SPAIN

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

SWEDEN

Sköldkörtelförbundet
<https://skoldkortelforbundet.se/>

UNITED KINGDOM

The Thyroid Trust
www.ThyroidTrust.org

UNITED STATES OF AMERICA

Graves' Disease & Thyroid Foundation
<https://gdatf.org/>

