Thyroid Federation International

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WORLD IODINE DEFICIENCY PREVENTION DAY

October 21 marks World Iodine Deficiency Prevention Day.
We want to highlight the key role of iodine for thyroid health.

Newsletter, October 2026

Thyroid Federation International

2026 TFI TEAM

President
Ashok Bhaseen (Canada)

Vice President
Linda Henderson (Spain)

Secretary
Beate Bartès (France)

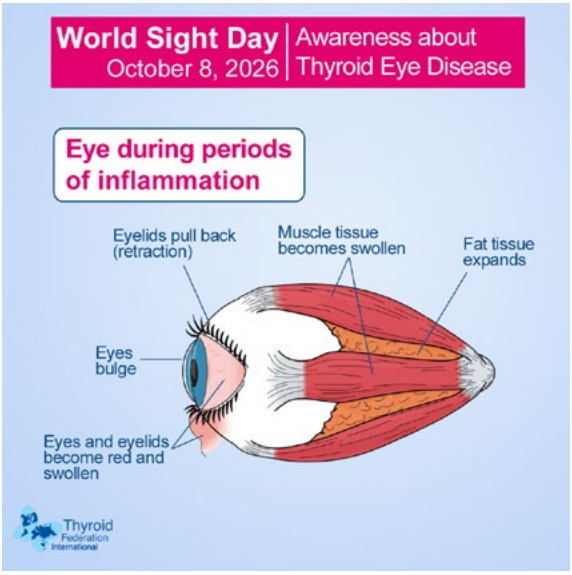
Treasurer
Giulia Giombolini (Italy)

Executive Director
Anna Bokor (Hungary)

Members at Large
Roko Granić (Croatia)
Nancy Patterson (USA)
Esther Bloem (The Netherlands)
Monika Schindler-Schnitzl (Austria)

Consultants
Katherine Keen, Administrative Coordinator (Canada)
Carlo Aragona, IT Consultant (Italy)





www.thyroid-federation.org

#ThyroidFederationInternational #TFI #thyroid #October #PatientsFirst

Thyroid Federation International works for the benefit of thyroid patients worldwide.

31ST TFI ANNUAL GENERAL MEETING PORTO, PORTUGAL SEPTEMBER 3-4, 2026





The Thyroid Federation International Team thanks everyone who participated either on-site or online in our Annual General Meeting, on September 3-4, in Porto, Portugal.

It was a pleasure seeing all of you! Thank you for the insightful and brilliant presentations from our members and our sponsors. This is always a time to connect and look forward to how we can help each other and work together.

TFI is very happy to have appointed Anna Bokor as TFI's Executive Director. In this role, she oversees TFI Operations and Communications. She works to develop strategy and leads TFI Communications on all TFI communication materials.

TFI welcomes two new Members at Large, Esther Bloem from the Netherlands and Monika Schindler-Schnitzl from Austria.













Saúde Porto!



Helena and Vesa Ilvesmaki, Anna Bokor, Maria Silyanovska, Roko Granić, Ulla Slama, Beate Bartés, Esther Bloem, Linda Henderson

TFI was delighted to host the following sponsors during our AGM:

MERCK AMGEN VIRIDIAN EGETIS THERAPEUTICS

argenx ethyrealbio Medtronic IBSA Institute Biochimique SA

From Our Sponsors

On September 28, 2026, Egetis Therapeutics AB announced that the U.S. Food and Drug Administration (FDA) has approved EMCITATE® (tiratricol), a thyroid hormone receptor agonist, for the treatment of peripheral thyrotoxicosis in adults and pediatric patients with monocarboxylate transporter 8 (MCT8) deficiency (Allan–Herndon–Dudley syndrome). This is an important milestone for the MCT8 deficiency community and the broader rare disease community.

EMCITATE® is the first and only FDA-approved treatment of peripheral thyrotoxicosis in adults and pediatric patients with monocarboxylate transporter 8 (MCT8) deficiency in the United States. The FDA approval of EMCITATE was supported by a comprehensive clinical development program evaluating EMCITATE in patients with MCT8 deficiency, including ReTRIACt, Triac Trial I, Triac Trial II, Erasmus Medical Center (EMC) Cohort Study, EMC Survival Study and the U.S. Expanded Access Program.

“Today marks a turning point for patients living with MCT8 deficiency and their caregivers, who have waited long for an approved treatment in the United States. Our immediate focus is ensuring that eligible patients can access EMCITATE as quickly as possible,” said Nicklas Westerholm, Chief Executive Officer of Egetis Therapeutics.

”Early diagnosis is critical so that patients can be appropriately evaluated, connected with specialists and receive coordinated multidisciplinary care. The FDA approval of EMCITATE provides physicians in the United States with the first approved treatment option for patients and represents an important advance for the MCT8 deficiency community,” said Andrew J. Bauer, M.D., Pediatric Endocrinologist and Principal Investigator in ReTRIACt trial and Triac Trial II, evaluating EMCITATE in MCT8 deficiency.

About MCT8 Deficiency

MCT8 deficiency is a rare, devastating, life-limiting, X-linked disorder caused by pathogenic mutations in the SLC16A2 gene. These mutations impair the function of MCT8, a critical cell-surface thyroid-hormone transporter responsible for thyroid hormone transport in specific cells, including in the brain. As a result, patients experience disrupted thyroid hormone signaling, characterized by insufficient
thyroid hormone activity in the central nervous system and excessive exposure to the active thyroid hormone triiodothyronine (T3) in peripheral tissues. This leads to a complex disorder characterized by severe neurodevelopmental impairment and persistent peripheral thyrotoxicosis. The elevated T3 concentrations in peripheral tissues can result in a chronic hypermetabolic state affecting multiple organs, including the heart, muscles, liver, and kidneys. Clinical manifestations may include failure to thrive, cardiovascular strain, muscle wasting, metabolic imbalance, and increased susceptibility to infections. These systemic consequences of persistent thyrotoxicosis are believed to contribute significantly to the increased morbidity and premature mortality associated with the disorder. Patients with MCT8 deficiency have a reported median life expectancy of approximately 35 years.

Congratulations to Egetis Therapeutics for this important achievement!

Thyroid Federation International remains committed to collaborating to increase knowledge and awareness about MTC8 Deficiency and work for the benefit of patients with this ultra rare disease.

Thank You to our Sponsors

This year, Ashok Bhaseen, President, Linda Henderson, Vice President, and Beate Bartès, Secretary, have awarded our partners: Merck Healthcare, AMGEN, Viridian and IBSA for collaborating and helping us create lasting impact for thyroid patients.





ThyroWorld at ETA Conference

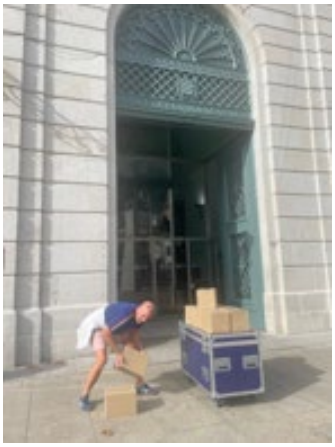
After having compiled, edited and finally printed over 1500 copies of the 29th volume of ThyroWorld, they had to be delivered to the ETA Porto congress venue in time to be placed into the delegates' bags. Thank you Beate and Roko for taking on such a "big and very heavy" task! Exhausting, but well worth it!

Thank you to all the editors of the ThyroWorld magazine: Beate Bartès, Roko Granić, Katherine Keen, Anna Bokor.





https://www.thyroid-federation.org/wp-content/uploads/2026/09/TW29_2026.pdf







EUROPEAN THYROID ASSOCIATION
PORTO, PORTUGAL



Ashok Bhaseen, TFI President, addressed the European Thyroid Association (ETA) Annual Meeting at the opening ceremony, September 5, 2026, highlighting the focus of our organization as a global, umbrella organization of thyroid patient associations. Our President gave an overview of our programs, projects, collaborations, partners, sponsors, and our work with the European Union and the WHO.





Ashok Bhaseen, along with Jan Maly, Director Policy, Merck Healthcare and Prof. Laura Fugazzola, President, European Thyroid Association at the Merck Healthcare's booth within the exhibition hall of the ETA congress, September 6, talking about the importance of ongoing policy advocacy for improvements in thyroid care in low- and middle income countries.

Events at the ETA Conference September 5, 2026



The members of TFI were very busy during the ETA meeting



Linda, Ashok, Anna at the Egetis Therapeutics booth



Leonidas Duntas, Ashok Bhaseen, Milos Zarkovic, Vanessa Ferreria





ADTI (Portuguese Patient Association) with Ashok Bhaseen

The Portuguese Thyroid Disease Association - Associação das Doenças da Tiróide (ADTI) and TFI co-hosted a 'Coffee with the Specialist' session, held in connection with the ETA Congress in Porto, September 5. As part of the event, patients had the opportunity to have a thyroid ultrasound and ask questions and discuss thyroid conditions with endocrinologists.

Iodine Global Network (IGN)



Linda Henderson, Vice President and Anna Bokor, Executive Director, attended the Iodine Global Network (IGN) Session, September 5, organized within the ETA Congress. The IGN side event brought together researchers, clinicians, healthcare professionals, representatives of iodine industry, and representatives of patient organizations dedicated to exploring practical, coordinated solutions for improving iodine nutrition.

We want to thank the European Thyroid Association and Iodine Global Network for the opportunity to present the EUthyroid2 project at the meeting. A special thank you to colleagues from World Iodine Association, Attilio Caligiani and Daniel Pizzaro for the two brilliant presentations and the kind invitation for a lunch after the meeting.



Linda Henderson, Anna Bokor, TFI
Henry Völzke (EUthyroid2)
Attilio Caligiani, Daniel Pizzaro (WIA)



Henry Völzke (EUthyroid2)
Attilio Caligiani, Daniel Pizzaro (WIA)

Look What We've Been Doing...

European Society for Paediatric Endocrinology, Marseille, France



ESPE European Society for Paediatric Endocrinology

Ashok Bhaseen and Beate Bartès attended the European Pediatric Endocrinology Congress, in Marseille (September 8-10), with a stand for our organization. Ashok spoke about the importance of normal growth in children. He highlighted that hormone health (e.g., thyroid hormone) is essential for linear growth, skeletal maturation, and overall physical and neurological development in children.



With Dr Yelna and Karin both from Armenia and Beate at the ESPE 2026 at the Networking reception





Interview on growth in children

Polish Academy of Sciences, Paris, France



"New challenges and treatment of selected endocrinopathies and co-occoring diseases in the light of current recommendations"



"During the meeting of the Polish Academy of Science in Paris today, Ashok Bhaseen suggested many interesting points for diet changing and spoke about selenium and iodine supplementation during treatment... I think it is a very good option because if we have the desired amount of supplementation (in patients that are lacking), we can prevent thyroid diseases."



Artur Bossowski
Medical University of Bialystok, Poland

Thank you to the Academy, who took care of my stay and meals. Dr. Arthur Bosowiski has been an excellant host, always highlighting the importance of TFI in his introductions and presentation.
Ashok Bhaseen



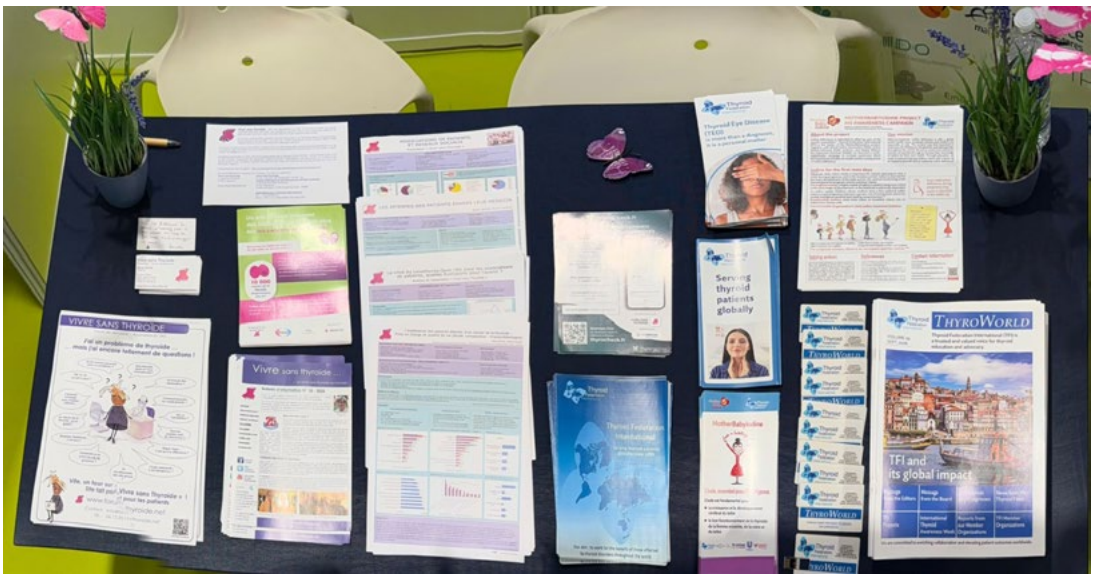
... and Look What Our Member Organisations have Been Doing

France - Vivre Sans Thyroïde

On October 7-9, the French thyroid patient association Vivre sans Thyroïde, as every year, attended the congress of the French Endocrine Society SFE in Bordeaux, with a booth presenting leaflets and newsletters both from VST and TFI, conferences and many interesting exchanges with endocrinologists from many French-speaking countries.







Germany - Bundesverband Schilddrüsenkrebs – Ohne Schilddrüse leben e.V.

On October 2-4, 2026, the German organisation for thyroid cancer patients Ohne Schilddrüse Leben - Bundesverband Schilddrüsenkrebs had its annual “autumn meeting” for patients, with medical conferences, roundtables, personal discussions and also some leisure time, in the beautiful city of Heidelberg.







Beate Bartès with Harald Rimmele and colleagues at the meeting

Italy - AIBAT (Member of CAPE)

The Italian Association of Graves' Disease and Thyroid Patients, AIBAT, held a meeting: 'Small Gland, Essencial Balance', in Reggio Emilia, Italy. The event brought together thyroid patients and thyroid experts in Endocrinology and Thyroid Eye Disease.







Portugal/ADTI

The initiative took place on September 2, 3, and 4, 2026, at the Trindade Metro Station in Porto, drawing a large turnout.

The event provided an opportunity for the early detection of disorders such as hypothyroidism — a condition resulting from an underactive thyroid that causes symptoms like feeling cold, fatigue, and depression. Many people passed through the Trindade metro station during the three days of screening, demonstrating significant interest in their thyroid health.

This initiative was organized by ADTI (Association for Thyroid Diseases) with the support of SPEDM (Portuguese Society of Endocrinology, Diabetes, and Metabolism) and Merck; it preceded the European Thyroid Association Annual Meeting, which was held this year in Porto, Portugal.





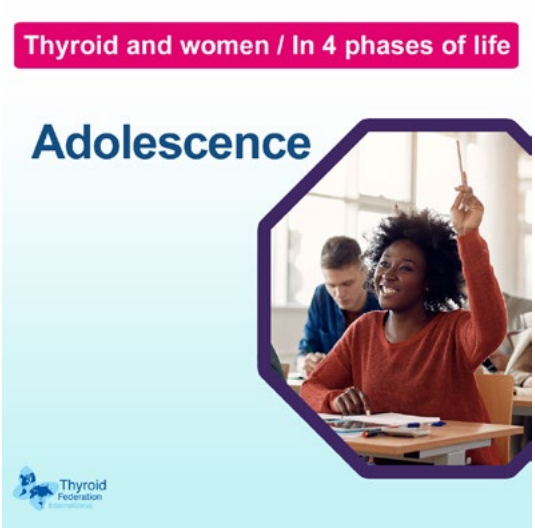


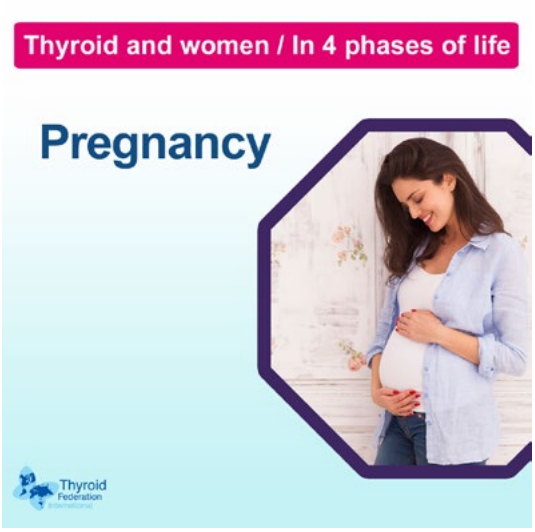


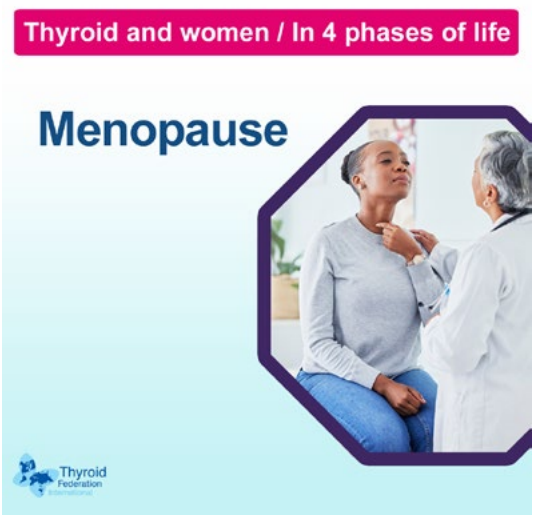
2027 International Thyroid Awareness Week

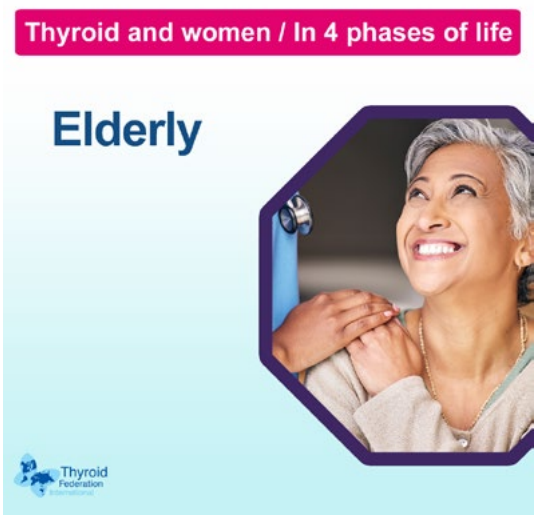
We are pleased to announce the theme of the 2027 International Thyroid Awareness Week:

Women and Thyroid - Four Phases of Life









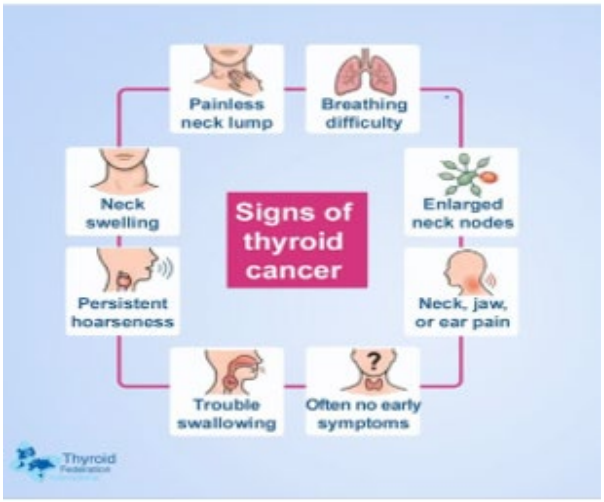
TFI Communications













Upcoming 2026 Meetings











Webinar



https://www.thyroid-federation.org/media/webinar/



The TFI Team
(L-R) Beate Bartes, Secretary; Esther Bloem, Member at Large; Giulia Giombolini, Treasurer; Anna Bokor, Executive Director; Roko Granić, Member at Large; Linda Henderson, Vice President; Monka Schindler-Schnitzl, Member at Large; Ashok Bhaseen, President; Carlo Aragona, IT Consultant



