

# TIF NEWSLETTER



**June 2024**  
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[www.thalassaemia.org.cy](http://www.thalassaemia.org.cy)



# COUNTRIES CORNER

*Offering expertise and support to patient associations worldwide.*

## CYPRUS



The Medical School of the University of Nicosia awarded an honorary doctorate to Mr. Panos Englezos, TIF's President, during the 2024 graduation ceremony. This prestigious recognition was given for Mr. Englezos' long-standing efforts in advocating for the rights and enhancing the quality of life for patients with thalassaemia, other haemoglobinopathies, and rare diseases, both nationally and internationally.

As one of TIF's founding members, as well as the Cyprus Thalassaemia Association and the Cyprus Alliance for Rare Diseases (CARD), Panos Englezos played a crucial role in promoting awareness, recognition, and management of thalassaemia under the National Disease Prevention Programme in Cyprus.

His voluntary contributions span over five decades, transcending borders, and have been instrumental in establishing TIF, which, since 1986, has been working to improve medical care, social integration, and patient support for individuals with haemoglobinopathies.



The Thalassaemia Society of Mauritius, in collaboration with the Thalassaemia International Federation, hosted Prof. Antonio Giulio Piga, a renowned haematologist from Italy, for a one-week visit from April 14 to April 10, 2024.

## MAURITIUS



The primary goals of Prof. Piga's visit were to advocate with the Ministry of Health and Wellness for the adoption of a second oral iron chelation option and to establish MRI T2\* assessments for evaluating cardiac and liver iron overload in regularly transfused patients.

During his visit, Prof. Piga also consulted around 50 patients across four regional hospitals, with a particular focus on those needing expert advice in conjunction with their current treating physicians.



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## COLLABORATION FOR A CAUSE:

### INSIDE TIF'S PAN-ARAB SUMMIT ON HAEMOGLOBINOPATHIES

The **"1st Pan-Arab Regional Summit on Haemoglobin Disorders,"** hosted by TIF's Arab Thalassaemia Associations' Forum (TATAF), was held on April 29, 2024, at the Hilton Hotel Nicosia in Cyprus.

The event, conducted under the patronage of Mr. Michael Damianos, Minister of Health of the Republic of Cyprus, brought together leading experts and policymakers to address the region's unmet healthcare needs. They presented evidence-based solutions aimed at enhancing or updating policies relevant to individuals with thalassaemia and other hemoglobinopathies across the Arab world.

The summit commenced with welcoming remarks from TIF's President Mr. Panos Englezos, and Former President Mr. Costas Papageorgiou. Dr. Hanan Balkhy, Regional Director of WHO/EMRO, and Dr. Mondher Letaief, WHO/EMRO Regional Advisor on Patient Safety, delivered distinguished addresses.

Speakers included Prof. Ali Taher, American University of Beirut; Prof. John Porter, University College Hospital, London; Prof. Dimitrios Farmakis, University of Athens Medical School; Dr. Sotiroulla Christou from the Cyprus Thalassaemia Centre; and TIF's Medical Advisor, Dr. Michael Angastiniotis.

Additionally, discussions were held featuring voices from patient-centered organizations, including Ms. Michele Abi Saad, Director of the Chronic Care Centre in Beirut; Ms. Stella Mina, Representative of the Hellenic Thalassaemia Association; and Mrs. Manal Zaatar, from the Arab Thalassaemia Associations of Egypt.

The summit successfully concluded with a consensus on 12 critical policy points to be advocated for full implementation by governmental healthcare authorities.





# TOPICS-IN-FOCUS

Targeted information on TIF's key activities and standout projects.

## TIF AT THE WHA77:

### DISCUSSIONS SHAPING THE FUTURE OF GLOBAL HEALTH

Under the direction of Dr. Androulla Eleftheriou, the Thalassaemia International Federation (TIF) CEO, the organization's involvement in the 77th World Health Assembly was remarkably successful.

On 31 May 2024, TIF and the World Federation of Hemophilia (WFH), under the sponsorship of the Ministry of Health of Cyprus, organized a side event focused on advanced therapies for hemoglobinopathies and bleeding disorders. This event aimed to spotlight global disparities in access to these therapies, foster collaboration among stakeholders, and address the logistical, financial, and bureaucratic obstacles impeding the availability of novel treatments.

Dr. Eleftheriou highlighted TIF's position that all patients should have access to safe and approved therapies.

### TIF'S AGENDA:

- Access to innovative medicines and therapies
- Promoting Cyprus's programme for haemoglobinopathies
- Advocating for resolutions on haemoglobinopathies and rare diseases.



Brian O'Mahony, CEO of the Irish Hemophilia Society, highlighted global disparities in healthcare access, noting significant barriers such as cost, national healthcare priorities, and the lack of patient registries

Natasha Azzopardi Muscat, Director of Health Policies and Systems at WHO EURO referenced the WHO's Novel Medicines Platform (NMP) as crucial for promoting communication and knowledge sharing. Muscat called for regional collaboration to ensure collective efforts towards access to innovation.



Organisers and participants committed to continuing the dialogue at the next World Health Assembly, aiming to establish regional cooperation platforms and strengthen WHO member states' health systems.



# TOPICS-IN-FOCUS

Targeted information on TIF's key activities and standout projects.

## INTERNATIONAL THALASSAEMIA DAY 2024:



INTERNATIONAL  
THALASSAEMIA  
DAY 2024

ACTIVITIES REPORT

[thalassaemia.org.cy/itd2024](http://thalassaemia.org.cy/itd2024)

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International Thalassaemia Day (ITD), with an impressive 30-year legacy, has firmly established itself as a significant event in the global health arena. This yearly observance has evolved into a worldwide initiative advocating for ongoing engagement and substantial change, passionately supporting thalassaemia communities around the world.

Under the theme "**Empowering Lives, Embracing Progress: Equitable and Accessible Thalassaemia Treatment for All**," ITD2024 mobilized a global audience to advocate for fair and inclusive healthcare and treatment for thalassaemia.

This year's campaign featured:

- The 'Your Story, Your Journey' platform, encouraging an open dialogue and sharing experiences and stories related to thalassaemia,
- The 'Bring Thal to Life' initiative, calling on individuals and organizations to join a global movement illuminating landmarks in red on May 8th, and
- The Events Map, where members, associates, and other stakeholders were encouraged to showcase their events and activities leading up to ITD2024, and much more.

The Thalassaemia International Federation (TIF) extends its sincere thanks to each and every supporter who played a role in propelling this movement forward. Together, we can bring the vision of equitable treatment closer to reality for every individual affected by thalassaemia!

- **Over 250 events** and activities were conducted across 104 countries.
- **78 landmarks and buildings** were illuminated worldwide.
- More than **20,000 campaign materials** were downloaded.



# INTERNATIONAL RELATIONS

*Advocating for patient rights and promoting cross-border sharing of expertise.*

## EHA2024: TIF WINS PRESTIGIOUS HEMASPHERE AWARD

The Thalassaemia International Federation (TIF) participated in the **29th EHA Annual Congress**, which took place in a hybrid format from June 13 - 16, 2024, in Madrid, Spain.

Highlighting its significant contributions to the field of Haematology, TIF was honored with a HemaSphere Award for their publication, "2021 Thalassaemia International Federation Guidelines for the Management of Transfusion-Dependent Thalassaemia."

Receiving the prestigious award on behalf of TIF was Mr. Loris Brunetta, a member of TIF's Board. The award ceremony also saw attendance from the distinguished authors of the publication—Professors Ali Taher, Maria D. Cappellini, John Porter, and Dimitrios Farmakis. Additionally, Prof. Maria Domenica Cappellini was bestowed with the Jean Bernard Lifetime Achievement Award by EHA for her trailblazing contributions to Haematology over more than three decades.

In Madrid, Mr. Brunetta represented TIF and actively participated in various sessions. Furthermore, TIF's educational materials were showcased at the Patient Advocacy Hub, an exhibition booth for the EHA Patient Advocacy Group.

Dr. Androulla Eleftheriou, TIF's CEO, and Ms. Lily Cannon, TIF's Deputy Director, also contributed significantly by participating in numerous sessions online.





# INTERNATIONAL RELATIONS

Advocating for patient rights and promoting cross-border sharing of expertise.



TIF participated in the **26th European Congress of Endocrinology (ECE2024)** in Stockholm, Sweden, from 11 to 14 May 2024, which gathered over 3,000 delegates.

Dr. Maddalena Casale from Italy represented the Federation with a presentation on the significance of endocrinology for patients with haemoglobinopathies, providing valuable insights into their complexities.

Our informational booth, staffed by dedicated patient advocate Ms. Sawsan Ghzal, engaged attendees and shared our educational resources.

TIF made its mark at the prestigious **Annual Conference of the European Association for the Study of Liver (EASL)**, held in Milan, Italy on 5-8 June, 2024. Representing TIF were Assistant Professor of Internal Medicine-Hepatology, Dr. Emmanouil Sinakos from Greece, and Mr. George Constantinou, TIF's Vice-President of the Board of Directors and a seasoned patient advocate.



Dr. Sinakos presented on the need for enhanced research in liver diseases among those with haemoglobinopathies on 8 June. Mr. Constantinou discussed the essential integration of liver disease in multidisciplinary care for these patients on 5 June.



Represented by Mr. George Constantinou, TIF Vice President, TIF took part in the **European Commission DG Health and Food Safety Conference on the New Regulation on Substances of Human Origin (SoHO)** on 24 June, in Brussels.

Key topics included new safety and quality regulations, innovation, and supply continuity of SoHO products across the EU Member States. Mr. Constantinou delivered a 5-minute impact statement on the importance of safety and quality in SoHO for those living with thalassaemia.



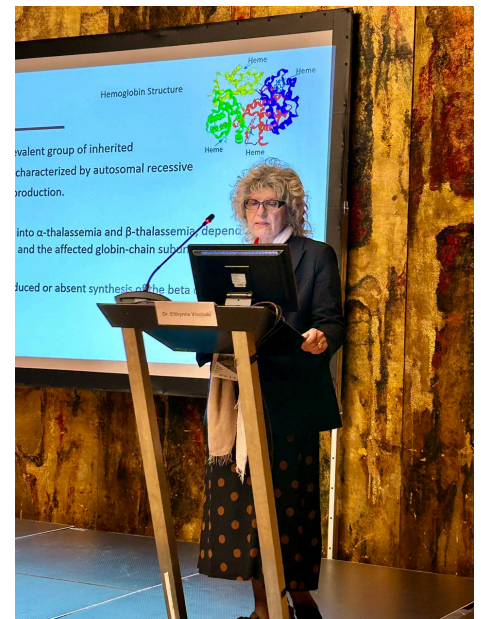
# EDUCATIONAL ACTIVITIES

*Providing lifelong education opportunities to patients, caregivers, and healthcare professionals worldwide.*

## TIF CAPACITY BUILDING WORKSHOP & 1ST RAIN SUMMIT

Over 150 representatives from patient associations, patients, caregivers, and researchers, along with medical experts in thalassaemia and haemoglobinopathies, gathered in Bucharest, Romania from May 16-19, 2024, for the TIF Capacity Building Workshop. The event featured networking and knowledge exchange on cutting-edge research and treatment advancements in haemoglobinopathies.

Attendees from over EU and non-EU 25 countries, including Cyprus, Greece, Italy, the UK, Germany, Spain, Sweden, Romania, the US, Canada, Saudi Arabia, Maldives, India, and Malaysia actively participated. The workshop emphasized patient education and skill-building to enable active involvement in decision-making and health policy.



The agenda included an opening ceremony and seven sessions led by experts from various countries. Topics covered were:

- Clinical management fundamentals of Haemoglobin Disorders
- Multidisciplinary care
- New Advances in the treatment of Thalassaemia and SCD
- National challenges
- Living with Thalassaemia - Opportunities, challenges & dilemmas

Concurrently with the workshop, the 1st Rare Anaemias International Network (RAIN) Patients' Summit was held, with the aim to facilitate an open dialogue between healthcare professionals and patients, offering a thorough exploration of current research, treatment options, and patient care strategies specific to rare anaemias.

**WATCH NOW**

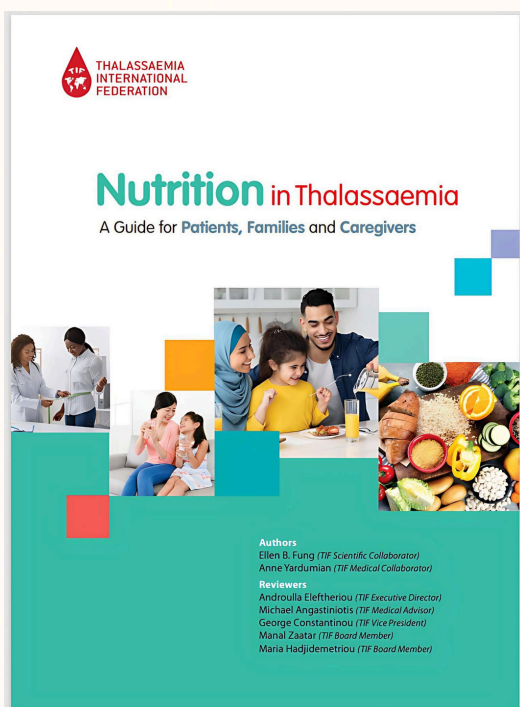
**TIFLIX**



# TIF PUBLICATIONS

TIF-generated publications, e-courses, and resources for patients and healthcare professionals.

## NUTRITION IN THALASSAEMIA: A GUIDE FOR PATIENTS, FAMILIES & CAREGIVERS



TIF's latest publication, "Nutrition in Thalassaemia: A Guide for Patients, Families, and Caregivers," offers clear and concise nutrition-related information for those affected by thalassaemia.

The guide covers:

- Nutritional needs specific to thalassaemia
- Nutritional assessment methods
- Key nutrients for thalassaemia patients
- The role of diet in managing thalassaemia complications

Authored by Dr. Ellen Fung, PhD, RD, CCD, and Dr. Anne Yardumian, Consultant Haematologist, MD, this publication provides practical recommendations to address nutritional deficiencies, toxicities, and other diet-related challenges.

[Read More >](#)

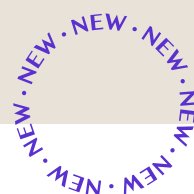
## E-COURSE ON EU HEALTH POLICY

Specifically crafted for individuals living with thalassaemia, sickle cell disease, and other rare anemias across the 27 EU countries, TIF's "EU Health Policy Course" is perfect for those eager to explore the realm of EU health policies and take charge of their healthcare journey.



The course comprises 5 comprehensive units, covering topics such as cross-border health, blood availability and safety, and the journey of medicines from the lab to regulatory approval. These units are designed to equip you with the knowledge needed to navigate the EU health policy landscape and exercise your rights effectively.

Discover more at: [EU Health Policy Course](#)



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