THALASSAEMIA INTERNATIONAL FEDERATION

ΕΛΛΗΝΙΚΗ ΟΜΟΣΠΟΝΔΙΑ ΘΑΛΑΣΣΑΙΜΙΑΣ



CONNECT.
LEARN.
LEAD.

CAPACITY-BUILDING WORKSHOP

20-22 NOVEMBER 2026 | **TITANIA HOTEL ATHENS, GREECE**

For Patients & Associations

Held alongside TIF's 2026 Annual General Assembly

HIGHLIGHTS

01 **CURATIVE APPROACHES: PAST, PRESENT AND FUTURE**
Stem cell transplantation, gene therapy and the experiences of patients who have undergone curative treatment.

02 **NEW ADVANCES IN CARE**
Advanced therapy medicinal products, newly approved treatments and updates from clinical trials.

03 **DEFINING QUALITY IN CARE**
Guidelines, multidisciplinary and patient-centred care, reference centres, networks and registries.

04 **CONNECTING PEOPLE ACROSS REGIONS**
Experiences and shared priorities from TIF regional networks in the Americas, Arab region, Indian subcontinent, ASEAN-West Pacific and NORDIC region.

05 **PRACTICAL TOOLS FOR PATIENT ASSOCIATIONS**
Artificial intelligence, effective communication and TIF resources for empowering patients and organisations.

06 **ADVOCACY AND SUSTAINABLE ORGANISATIONS**
Turning the patient voice into policy, responding to emerging challenges, and strengthening governance, funding and partnerships.

07 **LEARNING FROM SUCCESSFUL MODELS**
Experiences and best practices from India, the United States and Greece, with opportunities for discussion and shared learning.

INTRODUCTION

The **Thalassaemia International Federation (TIF)** welcomes patient association representatives, patient advocates, healthcare professionals and international partners to the **Patient Associations Capacity Building Workshop,** taking place from **20 to 22 November 2026 at the Titania Hotel in Athens, Greece.**

Organised in the context of **TIF's Annual General Assembly,** the workshop brings together the global haemoglobin disorders community to exchange experiences, strengthen patient leadership and advocacy, and promote patient-centred care for people living with thalassaemia, sickle cell disease and other haemoglobin disorders.

The programme connects developments in treatment and quality of care with the practical needs of patient associations. Expert presentations, patient testimonials, regional experiences and panel discussions will support participants in building effective, sustainable organisations and translating the patient voice into action.

OBJECTIVES

- Strengthen understanding of curative approaches, emerging therapies and developments in the care of haemoglobin disorders.
- Promote quality, multidisciplinary and patient-centred care informed by guidelines, reference centres, networks and registries.
- Equip patient representatives to advocate effectively and contribute to healthcare policy and reform.
- Build organisational capacity through stronger governance, sustainable funding and partnerships.
- Develop practical skills in communication and the use of artificial intelligence and TIF educational resources.
- Strengthen regional collaboration and share successful approaches that associations can adapt in their own countries.

SPEAKERS & CHAIRPERSONS

Name	Affiliation
Abi Saad, Michele	TIF Board Member, Chronic Care Center, Beirut, Lebanon
Abou Hamia, Diana	Beta-thalassaemia major survivor, Lebanon
Brunetta, Loris	TIF Treasurer, Associazione Ligure Thalassemici Board Member, Italy
Calabria, Bessie	TIF Board Member, Thalassemia Foundation of Canada Board Member
Cannon, Lily	Deupty Director, Thalassaemia International Federation, Cyprus
Chan, Marissa	Patient testimonial speaker, United Kingdom
Constantinou, George	TIF Vice President, United Kingdom
Delicou, Sophia	Clinical Haematologist, Hippokrateio General Hospital, Head of the Thalassaemia and Sickle Cell Unit and Expertise Centre of Haemoglobinopathies and Their Complications, Athens, Greece
Dimopoulou, Maria	Haematologist, Laikon General Hospital of Athens, Head, Thalassemia Unit, Hemoglobinopathies Expertise Center-Member of EuroBloodNet, Greece
Dimos, Vasilis	President of the Hellenic Thalassemia Association, Member of the Board of Directors of TIF
Eleftheriou, Androulla	Executive Director, Thalassaemia International Federation, Cyprus
Eleftheriou, Perla	Consultant Haematologist, UCLH, Honorary Associate Professor of Haematology, UCL, London, United Kingdom
Eliades, Photis	Expert Patient and Patient Advocate, Thalassaemia International Federation, Cyprus
Englezos, Panos	President, Thalassaemia International Federation, Cyprus
Farmakis, Dimitrios	Associate Professor of Cardiology, Athens University Hospital Attikon, NKUA Medical School, Head of the Cardio-Oncology Clinic and Cardiac Clinic for Haemoglobinopathies, Greece
Ficarra, Robert	TIF Board Emeritus, TIF Founding Member, Cooley's Anemia Foundation (CAF) Executive Committee Member, CAF Representative to Thalassemia International Federation, USA
Ganescu, Radu Costin	President, Romanian National Coalition of Organisations for Patients with Chronic Conditions (COPAC), founding member, Romanian Association for People with Thalassaemia, Romania
Ghobali, Mohamed	Patient advocate, SOS Globi, AI professional, France
Hadjidemetriou, Maria	TIF Board Member, Cooley's Anemia Foundation Board Member, USA
Johari, Fazalena	Secretary, Federation of Malaysian Thalassaemia Societies, Malaysia
Kulozik, Andreas	Professor of Pediatrics, University of Heidelberg, Chairman, Department of Pediatric Oncology, Hematology and Immunology, Director of the Clinical Program, Hopp Children's Cancer Center (KiTZ), Co-Director, EMBL/Medical Faculty Molecular Medicine Partnership Unit, Director, Clinical Cooperation Unit "Pediatric Leukemia", German Cancer Research Center (DKFZ), Germany
Maulana, Adhitya	Member, Yayasan Thalassaemia Indonesia, Member, ASEAN–West Pacific Network, Indonesia
Michalaki, Eleni	Vice President of Greek Thalassaemia Federation (EOTHA), Greece
Mina, Stella	Greek Thalassaemia Federation (EOTHA) Board Member, MSc, Developmental and School Psychologist, Greece
Mukherjee, Anubha Taneja	TIF Board Member, Thalassemics India, Attorney-at-Law, New Delhi, India
Pelides, Katia	Senior Educational Programme Officer, Thalassaemia International Federation, Cyprus
Piga, Antonio	Professor of Pediatrics, University of Torino, Italy
Saleem, Jeehan	Maldives Thalassaemia Society, Maldives
Steagall, Dina	Member, ABRASTA, Social Entrepreneur, Vice-President, ABRALE – Brazilian Association of Blood Cancer, Brazil
Tuli, Shobha	TIF Board Member and Secretary, Thalassemics India, New Delhi, India
Vlachaki, Efthymia	Professor, School of Medicine (AUTH), 2nd Department of Internal Medicine / Department of Pathology, Greece
Yannaki, Evangelia	Affiliate Professor, University of Washington, Seattle, Director, Gene and Cell Therapy Center, Hematology Department–BMT Unit, G. Papanicolaou Hospital, Thessaloniki, Greece

PROGRAMME

FRIDAY, 20 NOVEMBER - DAY 1

14.00 - 15.30	**REGISTRATIONS**	

15.30 - 16.15	**Opening Ceremony**	**Photis Eliades**
15.30 - 15.55	**Welcome Address** • **Panos Englezos,** *President, Thalassaemia International Federation (TIF)* • **Representative,** *Greek Thalassaemia Federation (EOTHA)* • **H.E. Mr Adonis Georgiades,** *Greek Minister of Health* • **Lilian-Venetia Vildiridi,** *Secretary General for Health Services, Ministry of Health, Greece* • **Eleni Tsagkari,** *President, National Blood Donation Centre* • **Ioannis Vardakastanis,** *President, National Confederation of People with Disabilities*	

16.15 - 17.30	**Session 1: Curative Approaches in Haemoglobin Disorders** Past, Present and Future	**Antonio Piga & Maria Dimopoulou**
16.15 - 16.35	Updates on Curative Approaches (HSCT and GE)	**Evangelia Yannaki**
16.35 - 16.55	An Update on Gene Addition Therapy	**Andreas Kulozik**
16.55 - 17.15	Patient Perspectives • Living Beyond Gene Therapy - A patient's personal experience • Life After Haematopoietic Stem Cell Transplantation (HSCT) - A patient's personal experience	**Marissa Chan** **Diana Abou Hamia**
17.15 - 17.30	Questions & Answers	

17.30 - 18.00	**COFFEE BREAK**

18.00 - 19.00	**Session 2: Transforming Haemoglobin Disorders** New Advances in Care	**Perla Eleftheriou & Sophia Delicou**
18.00 - 18.20	Advanced Therapy Medicinal Products (ATMPs): Transforming Lives: Are They with Us?	**Sophia Delicou**
18.20 - 18.50	Emerging Therapeutic Advances in Thalassaemia and Other Haemoglobin Disorders: Newly Approved Products and Clinical Trials Update	**Antonio Piga**
18.50 - 19.00	Questions & Answers	

20.30	**DINNER - Hosted by Greek Thalassaemia Federation (EOTHA)** **Ticket admission only**

SATURDAY, 21 NOVEMBER - DAY 2

09.00 - 11.30	**Thalassaemia International Federation's (TIF) Annual General Assembly** *Open only to representatives of Full TIF Members*	
11.30 - 12.00	**COFFEE BREAK**	
12.00 - 13.30	**Session 3: Defining Quality in the Care of Haemoglobin Disorders**	**Andreas Kulozik & Efthymia Vlachaki**
12.00 - 12.20	Guidelines and their Role	**Dimitrios Farmakis**
12.20 - 12.40	Multidisciplinary and Patient-Centred Care	**Sophia Delicou**
12.40 - 13.00	Reference Centres, Networks and Registries	**Perla Eleftheriou**
13.00 - 13.20	EU and Other Regional Contributions to the Care of Haemoglobin Disorders	**Androulla Eleftheriou**
13.20 - 13.30	Questions & Answers	
13.30 - 15.00	**LUNCH BREAK**	
15.00 - 17.00	**Session 4: Connecting People** Experiences from TIF Regional Networks	**Fazalena Johari & Bessie Calabria**
15.00 - 15.20	Pan American Network for Haemoglobin Disorders (PANHD)	**Maria Hadjidemetriou**
15.20 - 15.40	TIF's Arab Thalassaemia Associations Forum	**Michele Abi Saad**
15.40 - 15.50	Indian Subcontinent Network for Haemoglobin Disorders	**Jeehan Saleem**
15.50 - 16.10	ASEAN–West Pacific Network	**Adhitya Maulana**
16.10 - 16.30	NORDIC Network for Healthcare Professionals	**Katia Pelides**
16.30 - 17.00	Panel Discussion	
17.00 - 17.30	**COFFEE BREAK**	
17.30 - 18.45	**Session 5: The Tools for Effective Progress**	**Loris Brunetta & Katia Pelides**
17.30 - 17.50	Artificial Intelligence (AI) and Patient Organisations (NGOs)	**Mohamed Ghobali**
17.50 - 18.10	Communication: Winning Your Audience	**Photis Eliades**
18.10 - 18.30	TIF Resources for Empowering Patients and Patient Organisations	**Lily Cannon**
18.30 - 18.45	Questions & Answers	

SUNDAY, 22 NOVEMBER - DAY 3

09.00 - 10.15	**Session 6: How Can Patient Organisations Achieve Progress?**	**George Constantinou & Stella Mina**
09.00 - 09.20	Power of Advocacy: Global Challenges and Emerging Threats Facing Patient Organisations	**Anubha Taneja**
09.20 - 09.40	Turning the Patient Voice into Policy and Healthcare Reform	**Costin Ganescu**
09.40 - 10.00	Building Sustainable Patient Organisations: Governance, Funding and Partnerships	**Dina Steagal**
10.00 - 10.15	Questions & Answers	

10.15 - 10.45	**COFFEE BREAK**

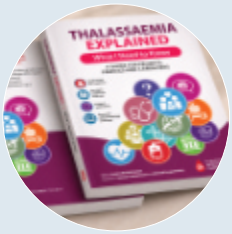
10.45 - 12.00	**Session 7: Successful Models and Best Practices from Around the World**	**Loris Brunetta & Eleni Michalaki**
10.45 - 11.05	**India -** Policy to Advocacy & Patnerships: Transforming the Haemoglobinopathy Landscape	**Shobha Tuli**
11.05 - 11.25	**USA -** Cooley's Anemia Foundation (CAF)	**Robert Ficarra**
11.25 - 11.45	**Greece -** Greek Thalassaemia Federation (EOTHA)	**Vassilis Dimos**
11.45 - 12.00	Panel Discussion	

12.00 - 12.30	**CLOSING CEREMONY** **Commitments and Next Steps** • **Panos Englezos,** *President, Thalassaemia International Federation (TIF)* • **Representative,** *President, Greek Thalassaemia Federation (EOTHA)*

Enjoying the Conference?
Let Us Know What You Think!

TIF RESOURCES

The latest TIF publications!



Thalassaemia Explained: What I Need to Know (2026)



Guidelines for the Emergency Management of Thalassaemia & Sickle Cell Disease – 2nd Edition (2026)



Guidelines for the Management of Thalassaemia Syndromes – Topics in Focus Series (2025)



A Guide for the Haemoglobinopathy Nurse (2025)



Know Your Rights: A Guide for People Living with Thalassaemia and Sickle Cell Disease (2025)



Nutrition in Thalassaemia: A Guide for Patients, Families and Caregivers (2024)



Guidelines for the Management of α-Thalassaemia (2023)



Nutrition in Thalassemia & PKD:A Guideline for Clinicians (2023)



Guidelines for the Management of NTDT β-Thalassaemia (3rd edition – 2023)

Other Resources



The TIF AI Knowledge Bot, available on TIF's website, provides immediate access to reliable, multilingual information on thalassaemia, based on TIF's scientific resources and supported by references to relevant sources.

Disclaimer: It does not replace professional medical advice, diagnosis or treatment.

TIFLIX

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THALASSAEMIA INTERNATIONAL FEDERATION

Thalassaemia International Federation
P.O.Box 28807, Nicosia 2083, Cyprus
Tel: +357 22319129
Fax: +357 22314552
Email: thalassaemia.org.cy