



**THALASSAEMIA
INTERNATIONAL
FEDERATION**

OFFICIAL PROGRAMME

PATIENT ASSOCIATIONS CAPACITY BUILDING WORKSHOP 2026

20-22 NOVEMBER 2026

Titania Hotel Athens

Panepistimiou 52, Athina 106 78, Greece

MASTER OF CEREMONIES / WORKSHOP MODERATOR

Photis Eliades

TIME	SESSION / ACTIVITY	SPEAKER
15:00 - 15:30	Registration & Welcome Coffee	
15:30 - 16:15	Opening Ceremony	
15:30 - 15:55	Welcome Addresses	Panos Englezos - TIF Maria Angelopoulou - EOTHA Greek Ministry of Health
15:55 - 16:15	Keynote Speech: The Contrasting Realities in the Control and Care of Haemoglobin Disorders	Androulla Eleftheriou
16:15 - 17:30	Session 1: Curative Approaches in Haemoglobin Disorders - Past, Present and Future	
	CHAIRPERSONS	Antonio Piga & Maria Dimopoulou
16:15 - 16:35	Updates on Curative Approaches (HSCT and GE)	Evangelia Yannaki
16:35 - 16:55	Gene Therapy: Real-World Evidence	Prof. Andreas Kulozik
16:55 - 17:15	Patient Testimonials Patient who has undergone gene therapy Patient who has undergone haematopoietic stem cell transplantation (HSCT)	Mr. Maloutas Vassilis Mr. Nikolopoulos Konstantinos
17:15 - 17:30	Q&A	
17:30 - 18:00	Coffee Break	
18:00 - 19:00	Session 2: Transforming Haemoglobin Disorders - New Advances in Care	
	CHAIRPERSONS	Perla Eleftheriou & Sophia Delicou
18:00 - 18:20	Advanced Therapy Medicinal Products (ATMPs): Transforming Lives - Are They with Us?	Androulla Eleftheriou
18:20 - 18:50	Emerging Therapeutic Advances in Thalassaemia and Other Haemoglobin Disorders Newly Approved Products and Clinical Trials Update	Antonio Piga

TIME	SESSION / ACTIVITY	SPEAKER
18:50 - 19:00	Q&A	
19:00 - 20:00	Welcome Reception TBC	

TIME	SESSION / ACTIVITY	SPEAKER
09:00 - 11:30	TIF Annual General Assembly Meeting Open only to representatives of TIF Full Members Separate agenda	
12:00 - 13:30	Session 3: Defining Quality in the Care of Haemoglobin Disorders	
	CHAIRPERSONS	Antonis Kattamis & 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	Q&A	
13:30 - 15:00	Lunch Break	
15:00 - 17:00	Session 4: Connecting People - Experiences from TIF Regional Networks	
	CHAIRPERSONS	Fazalena Johari & Bessie Calabria
15:00 - 15:20	Pan American Network for Haemoglobin Disorders	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	Shobha Tuli
15:50 - 16:10	ASEAN-West Pacific Network	Adhitya Maulana
16:10 - 16:30	NORDIC Network	Katia Pelides

TIME	SESSION / ACTIVITY	SPEAKER
16:30 - 17:00	Panel Discussion	
17:00 - 17:30	Coffee Break	
17:30 - 18:45	Session 5: The Tools for Effective Progress	
	CHAIRPERSONS	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	TBC
18:30 - 18:45	Q&A	

TIME	SESSION / ACTIVITY	SPEAKER
09:00 - 10:15	Session 6: How Can Patient Organisations Achieve Progress?	
	CHAIRPERSONS	George Constantinou & Stella Mina
09:00 - 09:20	Global Challenges and Emerging Threats Facing Patient Organisations	Lily Cannon
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 Steagall
10:00 - 10:15	Q&A	
10:15 - 10:45	Coffee Break	
10:45 - 12:00	Session 7: Successful Models and Best Practices from Around the World	
	CHAIRPERSONS	Gaia Cifone & E. Michalaki
10:45 - 11:05	India - Thalasseemics India	Anubha Taneja
11:05 - 11:25	USA - Cooley's Anemia Foundation	Robert Ficarra
11:25 - 11:45	Greece - Greek Thalassaemia Federation	Olga Kakaraki
11:45 - 12:00	Panel Discussion	
12:00 - 12:30	Closing Ceremony: Commitments and Next Steps TIF President and EOTHA President	