

Conference Programme

15th International
Conference on Thalassaemia
& Other Haemoglobinopathies

virtual

17th **&**
TIF Conference
for Patients & Parents

19-21 November 2021

www.tifeducation.org

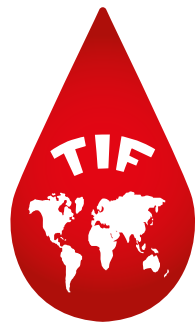
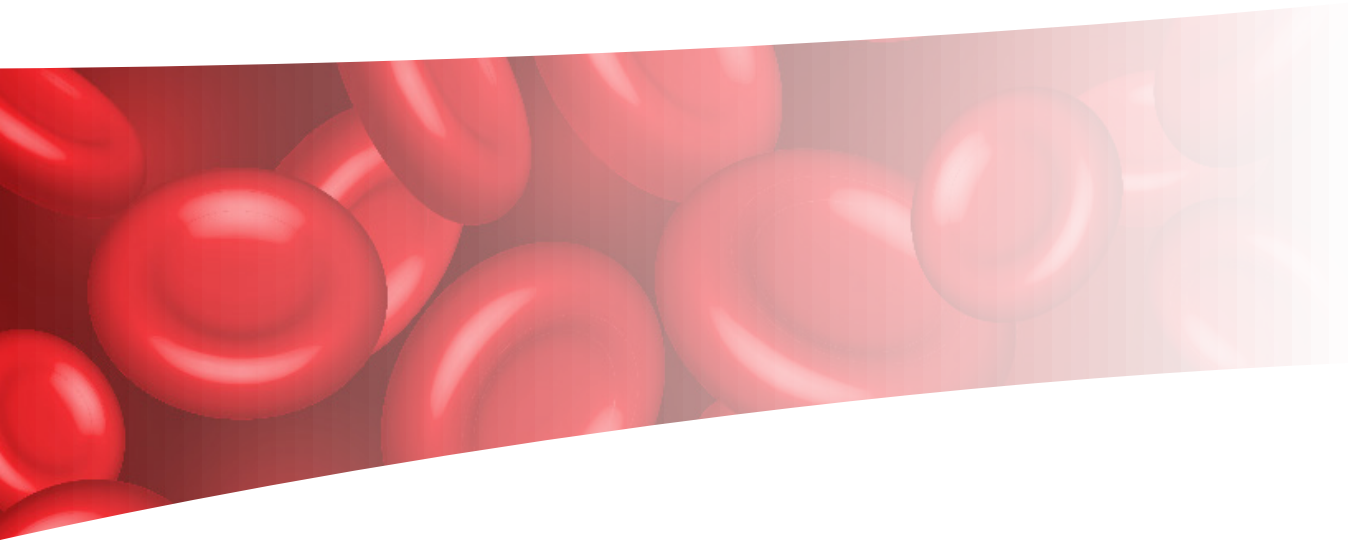
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**THALASSAEMIA
INTERNATIONAL
FEDERATION**



Welcome Message

Dear Friends,

We are privileged to cordially invite you to attend and participate in the upcoming 15th International Conference on Thalassaemia & Other Haemoglobinopathies & the 17th TIF Conference for Patients & Parents, to be held virtually on 19-21 November 2021.

Organised by the Thalassaemia International Federation (TIF), this conference promises to provide an outstanding opportunity for all involved stakeholders to bridge perspectives from various disciplines and to meet the challenges of improving the health and quality of life of those affected by haemoglobinopathies. This conference constitutes a unique forum for sharing knowledge and experiences and for building up new friendships, collaborations, partnerships and networks.

Following the global pandemic of COVID-19, this year's conference requires a different approach, to allow international engagement and ensure participant safety. For the first time our International Conference will be web-based. To make sure that the conference will maintain its top-quality educational level despite its virtual nature, we aim to organize an exciting, ground-breaking and highly educational scientific program, covering a broad range of thematic topics.

Due to the virtual nature of the conference, for the first time the Scientific Sessions are joint with the Patients Programme and promise very interesting lectures and discussions that appeal to all scientists, patients and parents who deal with Thalassaemia and other Haemoglobin Disorders. We are very excited to take this initiative.

We very much look forward to welcoming and seeing you all at this event, aiming to build a brighter future together for patients with haemoglobinopathies all over the world!

Cordially,

Mr Panos Englezos

President, Thalassaemia International Federation (TIF)

Dr Androulla Eleftheriou

Executive Director, Thalassaemia International Federation (TIF)



Committees

Conference Chairperson

Panos Englezos

President, Thalassaemia International Federation (TIF)

Organising Committee

Androulla Eleftheriou

Executive Director, Thalassaemia International Federation (TIF)

Michael Angastiniotis

Medical Advisor, Thalassaemia International Federation (TIF)

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TIF Board Member - Vice President, Thalasseemics India, India

**Names are in alphabetical order based on surname*



Friday, 19 November 2021

EET time	Main Hall
11.45 - 13.15	Session 1: Challenges & Unmet Needs: the Patient Perspective Chairs: E. Mylona & S. Tuli Are we near achieving optimal care in:
11.45 - 11.55	Europe G. Constantinou
11.55 - 12.05	Middle East E. Altaglubee
12.05 - 12.15	South East Asia V. Piplani
12.15 - 12.25	West Pacific F. Johari
12.25 - 12.35	North America R. Elbard
12.35 - 12.45	South America M. Steagall
12.45 - 13.15	Q&A
13.15 - 13.30	Comfort Break
13.30 - 14.45	PRESIDENTIAL SYMPOSIUM <i>Organised by Thalassaemia International Federation</i> The Global Unmet Needs of Patients with Haemoglobin Disorders Chairs: P. Englezos, C. Papageorgiou, R. Ficarra
13.30 - 13.45	Chronic Diseases and SDG2030 Goals P. Barango
13.45 - 14.00	Haemoglobin Disorders & Migration M. Angastiniotis
14.00 - 14.15	Combating Unmet Needs: TIF's contribution A. Eleftheriou
14.15 - 14.45	Panel Discussion
14.45 - 15.00	Comfort Break
15.00 - 16.00	Opening Ceremony
15.00 - 15.30	Opening Remarks Z. Jakab, <i>Deputy Director-General, World Health Organisation</i> S. Kyriakides, <i>European Commissioner, Health & Food Safety</i> Panos Englezos, <i>President of Thalassaemia International Federation</i>
15.30 - 16.00	TIF Award Ceremony



16.00 - 16.15	Comfort Break
16.15 - 18.15	MODERATED KEYNOTE SESSION: Haemoglobin Disorders in 2030 Chairs: A. Piga & G. Constantinou Panelists: M. Angastiniotis, MD. Cappellini, G. Constantinou, A. Eleftheriou, P. Englezos, D. Loukopoulos, A. Mehmood, J. Porter, A. Taher, A. Mukherjee, V. Viprakasit & M. Zaatar
18.15 - 18.30	Comfort Break
18.30 - 20.00	Session 2: Living with Thalassaemia & Sickle Cell Disease Chairs: G. Constantinou & H. Dahmani
18.30 - 18.45	Balancing education, employment, work, social life and health M. Miltiadous
18.45 - 19.00	Building truthful relationships – How and when do I tell my partner that I have a haemoglobin disorder? A. Mukherjee
19.00 - 19.15	How do I tell my child I have thalassaemia and what it means M. Hadjidemetriou
19.15 - 19.30	My thoughts, challenges and fears during COVID-19 pandemic L. Brunetta
19.30 - 20.00	Q&A



Saturday, 20 November 2021

EET time	Main Hall
09.30 - 11.00	Session 3: Clinical Management of Thalassaemia - TIF Guidelines Recommendations for TDT & NTDT Chairs: G. Dusheiko & D. Farmakis
09.30 - 09.45	Blood Transfusion F. Shah
09.45 - 10.00	Iron Monitoring and Chelation J. Porter
10.00 - 10.15	Cardiac Complications M. Walker
10.15 - 10.30	Liver Disease J. Koskinas
10.30 - 10.45	Bone Disease E. Terpos
10.45 - 11.00	Q&A
11.00 - 11.15	Comfort Break
11.15 - 12.45	Session 3 continued: Clinical Management of Thalassaemia – TIF Guidelines Recommendations for TDT & NTDT Chairs: A. Yardumian & J. Porter
11.15 - 11.30	Renal Disease A. Taher
11.30 - 11.45	Thrombosis MD. Cappellini
11.45 - 12.00	Pain P. Eleftheriou
12.00 - 12.15	Fertility & Pregnancy N. Skordis
12.30 - 12.30	Addressing Emergency Management J. Porter
12.30 - 12.45	Q&A
12.45 - 13.00	Comfort Break
13.00 - 14.30	Abstract Presentations Session Chair: M. Angastiniotis
13.00 - 13.10	Development and Quality Improvement Assessment of a Thalassemia Care Program S. Fritch Lilla



13.10 - 13.20	The Iran thalassemia prevention program: A maxim for other countries M. Hadipour
13.20 - 13.30	Diagnostic performance of a deep learning system for liver iron concentration measurement and comparison to a widely available T2* method M. House
13.30 - 13.40	The International Hemoglobinopathy Research Network (INHERENT): An International Initiative to Study the Role of Genetic Modifiers in Hemoglobinopathies K. Kuo
13.40 - 13.50	Genome Editing for Beta-Haemoglobinopathies Without Double-Strand DNA Cleavage N. Papaioannou
13.50 - 14.00	The ClinGen Hemoglobinopathy Variant Curation Expert Panel C. Stephanou
14.00 - 14.10	Efficacy and toxicity of Luspatercept in the treatment of Transfusion Dependent Thalassemia K. Toutoudaki
14.10 - 14.30	Q&A
14.30 - 14.45	Comfort Break
14.45 - 16.15	Session 4: Prevention of Haemoglobin Disorders Chairs: D. Loukopoulos & J. Old
14.45 - 15.00	Where are we today in the prevention of haemoglobin disorders M. Angastiniotis
15.00 - 15.15	Challenges in implementing National Prevention Programmes in the control of Haemoglobin Disorders: the global perspective M. Petrou
15.15 - 15.30	Potential sources of error in population screening for haemoglobin disorders A. Balassopoulou
15.30 - 15.45	New Laboratory approaches for Haemoglobin Disorders J. Traeger - Synodinos
15.45 - 16.15	Q&A
16.15 - 16.30	Comfort Break
16.30 - 18.25	Session 5: Innovation in Haemoglobin Disorders Chairs: A. Taher & A. Kattamis
16.30 - 16.50	Authorised and ongoing clinical trials of medical products & devices for the treatment of Thalassemia S. Rivella



16.50 - 17.10	Authorised and ongoing clinical trials of medical products & devices for the treatment of Sickle Cell Disease P. Eleftheriou
17.10 - 17.30	Exploring the Potential of Gene Silencing in Thalassemia G. Campion & A. Martinez
17.30 - 17.50	IMR-687, an Investigational PDE9 Inhibitor for SCD and Beta-thalassemia K. Attie
17.50 - 18.15	Q&A
18.15 - 18.30	Comfort Break
18.30 - 20.00	Agios Pharmaceuticals Satelite Symposium Pyruvate Kinase Activation: Update on Clinical Trial Results across Hemolytic Anemias Moderator/Chair: MD. Cappellini
18.30 - 18.40	Welcome and Introductions MD. Cappellini
18.40 - 19.05	Mitapivat in pyruvate kinase deficiency – results of pivotal clinical trials W. Barcellini
19.05 - 19.25	Activation of wild-type pyruvate kinase in thalassemia – clinical trial results MD. Cappellini
19.25 - 19.40	Activation of wild-type pyruvate kinase in sickle cell disease – preliminary findings E. van Beers
19.40 - 20.00	Q&A and concluding remarks



Sunday, 21 November 2021

EET time	Main Hall
11.00 - 13.00	Session 6: Sickle Cell Disease Chairs: A. Inati & I. Odame
11.00 - 11.15	Sickle Cell Disease in Childhood I. Odame
11.15 - 11.30	Sickle Cell Disease in Adulthood L. de Franceschi
11.30 - 11.45	Effective management of Pain Crises A. Inati
11.45 - 12.00	Emergency Care P. Telfer
12.00 - 12.25	Essential elements of Multidisciplinary Care in Sickle Cell Disease M. Abboud
12.25 - 12.50	Comparative Analysis of Guidelines/Standards for the Clinical Management of Sickle Cell Disease K. Musallam
12:50 - 13.00	Q&A
13.00 - 13.15	Comfort Break
13.15 - 14.30	Ice-Breaking Session 7: Case Presentations Chairs: F. Shah & P. Eleftheriou Speakers TBC
14.30 - 14.45	Comfort Break
14.45 - 16.30	Session 8: Curative Approaches in Haemoglobin Disorders Chairs: E. Yannaki & P. Sodani
14.45 - 15.05	Haploidentical Transplantation with Post-Cyclophosphamide in Thalassemia S. Hongeng
15.05 - 15.25	Haematopoietic Stem Cell Transplantation: Experience from India V. Matthews
15.25 - 15.45	Haploidentical transplantation in Thalassemia & SCD P. Sodani
15.45 - 16.05	Advances in Gene Therapy by Gene Addition (TDT and SCD) F. Locatelli
16.05 - 16.25	Advances in Gene Therapy by Genome Editing (TDT and SCD) C. Lederer
16.25 - 16.30	Q&A



16.30 - 16.45	Comfort Break
16.45 - 18.00	Session 9: Emerging Concepts and Challenges in Haemoglobin Disorders Chairs: MD. Cappellini & A. Kattamis
16.45 - 17.00	Ageing in Haemoglobin Disorders I. Motta
17.00 - 17.15	Solid & Haematological Malignancies A. Taher
17.15 - 17.30	Haemoglobin Disorders and COVID-19: A global snapshot MD. Cappellini
17.30 - 17.45	The importance of genotype/phenotype in clinical decisions: Does one size fit all? S. Christou
17.45 - 18.00	Q&A
18.00 - 18.15	Comfort Break
18.15 - 18.30	Closing Remarks Chairs: P. Englezos, A. Taher & J. Porter
	A new era is dawning for the cure and care of Haemoglobin Disorders. Will 50 years of knowledge and experience find political commitment for the implementation of radical policy changes?



Monday, 22 November 2021

EET time	Main Hall
10.00 - 11.00	TIF Consensus Meeting 1: Accurate Iron Load Monitoring Chair: A. Pepe
10.00 - 10.30	How accuracy and reliability are ensured in Iron Load Monitoring?
10.00 - 10.10	An overview of the best practices in clinical care to date: The Cardiologist's perspective M. Walker
10.10 - 10.20	An overview of the best practices in clinical care to date: The Hepatologist's perspective D. Kountouras
10.20 - 10.30	An overview of the best practices in clinical care to date: The MRI Specialist's perspective E. Alexiou
10.30 - 10.35	Why is this a concern for TIF? M. Angastiniotis & A. Eleftheriou
10.35 - 10.55	Setting standards for accurate ILM. Is it possible? Panel Discussion 10.55 - 11.00 Conclusions A. Eleftheriou & A. Pepe
11.00 - 11.15	Comfort Break
11.15 - 12.15	TIF Consensus Meeting 2: Chelation Drugs: Their Safety and Quality Chair: M. Hadipour
11.15 - 11.25	How is safety and quality of chelation drugs defined? J. Porter
11.25 - 11.35	Is continuous supply of drugs an element of safety? M. Angastiniotis & M. Abi Saad
11.35 - 11.50	What is the place and value of Generic formulations in a Healthcare System and what are the elements of safety involved in their use? The Thalassaemia perspective M. Hadipour
11.50 - 12.00	A CALL FOR ACTION NEEDED. What does this involve? A. Eleftheriou & M. Angastiniotis
12.00 - 12.15	Interactive Discussion
12.15 - 12.30	Comfort Break



12.30 - 13.30	TIF Consensus Meeting 3: Blood Safety & Adequacy Chair: C. Politis
12.30 - 12.45	Global overview of Blood Safety and Availability - The work of the WHO over the years on a recurring global issue Y. Maryuningsih
12.45 - 13.05	The work of the WHO Blood Reference Centres in Asia and the Middle Eastern Region The Sri Lankan Experience K. Edirisinghe The Iranian Experience P. Eshghi
13.05 - 13.20	The global patients' perspective, TIF's 2021 Global Review and the need for an International Alliance of Patients for Blood Safety and Adequacy A. Eleftheriou
13.20 - 13.30	Interactive Discussion
14.00 - 17.00	TIF Constitutional Assembly <i>by invitation only</i>
17.00 - 17.15	Comfort Break
14.00 - 14.45	TIF Board Meeting <i>by invitation only</i>
18.00 - 20.00	PKD Capacity Building Meeting - Detailed Programme TBA



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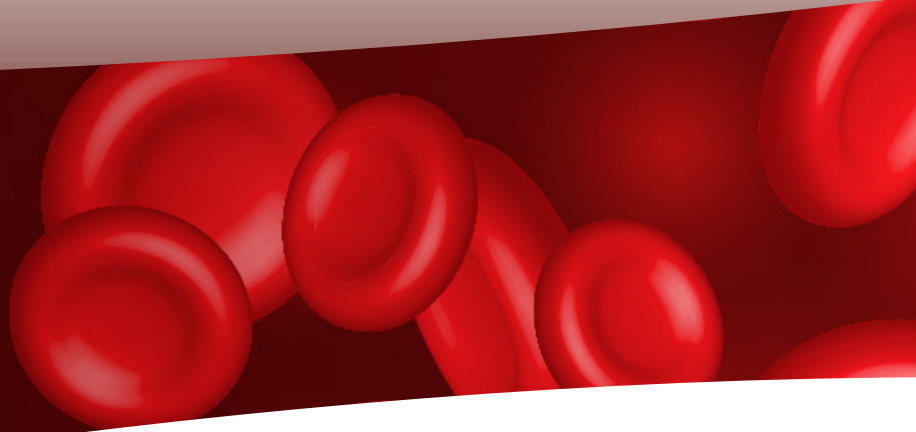


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