

Tuesday, 29 August 2023

**16th International Conference on Thalassaemia & Other
Haemoglobinopathies
&
18th TIF Conference for Patients & Parents**

3 – 5 November 2023
Grand Hyatt Hotel, Kuala Lumpur, Malaysia

Draft Patients/Parents Programme

Friday 3rd November 2023

15.00 – 17.00 TIF Board Meeting

18.00 – 19.00 **OPENING CEREMONY**

Master of Ceremonies:

Opening remarks by:

H.E. the Minister of Health – Malaysia, Dr Zaliha binti Mustafa
ASEAN (TBC)

WHO Director-General, Dr Tedros Adhanom Ghebreyesus [recorded message](#)

WHO Representative to Malaysia, Brunei Darussalam and Singapore, Dr Rabindra
Abeyasinghe,

(on behalf of WHO West Pacific Regional Office Director)

European Commissioner for Health & Food Safety, Dr Stella Kyriakides [recorded message](#)

Malaysian Haematology Society

Malaysian Association for Paediatric Haematology & Oncology

Federation of Malaysian Thalassaemia Societies

President of the Thalassaemia International Federation, Mr Panos Englezos

19.00 – 19.30 **KEYNOTE LECTURE**

The importance of thalassaemia to the global genome project

Prof. Zilfalil bin Alwi

UNESCO Chair in Human Genetics on Thalassaemia, Universiti Sains Malaysia

~END OF DAY~

Saturday 4th November 2023

09.30 – 10.45 **Capacity Building for National Thalassaemia Associations**

Chairpersons: TBC & TBC

Speaker

Essential components of successful Patient Associations

Healthcare Advocacy: How to be effective when engaging with decision-makers

Sharing success stories from:

- India – Thalassaemia named in the National Disability Law
- Indonesia – Full treatment coverage for thalassaemia in a country without Universal Health Coverage
- Greece – Social, Educational and Professional Benefits
- USA – Deferiprone FDA approval

Patient Involvement in national policy formulation for the control of thalassaemia – best practices from:

- Cyprus
- Italy
- United Kingdom

Common factors that have contributed to these successes
Discussion

10.45 – 11.15 COFFEE BREAK

PARALLEL ROOM: TIF General Assembly – *by invitation only*¹

10.45 – 12.30 TIF General Assembly

Moderator: A. Eleftheriou

- Report of 2018 – 2023 by the President:
 - Activities
 - Accounts
- Clarifying the new Constitution of TIF
- Explaining procedures for the election of the TIF Board of Directors
- Elections

11.15 – 12.30 Topics in Focus

Chairpersons: TBC & TBC
Transition from Paediatric to Adult Care
Overview of the Recommendations: Clinical Management of Thalassaemia (TIF's 2022/23 Guidelines)
The value of Multidisciplinary Care & Reference Centres
New advances in the prevention & care of haemoglobin disorders

Speaker

¹ Only representatives of TIF Members (Full and General) can participate

Discussion

12.30 – 14.00 LUNCH

12:30 – 13:15: 1st Meeting of the newly elected TIF Board of Directors

14.00 – 15.30 Policy Session: The next essential step

Chairpersons: TBC & TBC

The global reality as expressed by the patients

- **TIF's work in capturing the Patients' Perspective**
(7min video with extracts from patients' webinars)
- **Patient testimonies from around the world on their journey**
 - Middle East / North Africa
 - Europe
 - SouthEast Asia
 - West Pacific
 - Americas
- **Unmet needs: Inequalities: Violation of Patients' Rights**
- **Thalassaemia Patients Consensus Declaration presented to Policy Influencers**

Policy Influencer statements

(Statements from participating regional & international bodies – examples below)

- Ministry of Health – Malaysia
- ASEAN
- WHO - Rabindra Abeyasinghe (WHO Representative to Malaysia, Brunei Darussalam and Singapore)
- UNESCO Chair in Human Genetics on Thalassaemia, Universiti Sains Malaysia
- ISBT
- SEATHAF – Suthat Fucharoen

15.30 – 16.00 COFFEE BREAK

16.00 – 18.00 Meet the Experts

Coordinator:

Introductory Remarks: Basic Recommendations from TIF's Guidelines

Panellists answer questions

~END OF DAY~

Thematic unit 6. Challenges in service provision

09.00 – 09.20	Quality and safety of blood: where are we?	Speaker Erica Wood (Australia)
09.20 – 09.40	Availability and accessibility of iron chelation drugs: Challenges	Androulla Eleftheriou (Cyprus)
09.40 – 10.00	Quality standards for treatment centres and the need for Reference Centres and MDC	
10.00 – 10.15	Discussion	
10.15 – 11.00	Round-Table Discussion Quality of Life Measurements: Meaningful interpretations	Medical Perspective: Yesim Aydinok (Turkey)
	Moderator:	Patient Perspective: Veeresh Pavate (Canada)

11.00 – 11.30 COFFEE BREAK

11.30 – 13.30 Thematic unit 7. Complications of β -thalassaemia

	Chairpersons: Ong Gek-Bee (Malaysia)	Speaker
11.30 – 11.50	Heart disease: What is new?	D. Farmakis (Greece)
11.50 – 12.10	Liver disease: early diagnosis and treatment	MD Cappellini (Italy)
12.10 – 12.30	Malignancies in beta thalassaemia	Ali Taher (Lebanon)
12.30 – 12.50	Bone disease: how to prevent bone pain and complications	Antonio Piga (Italy)
12.50 – 13.10	Endocrinopathies	
13.10 – 13.30	Discussion	

13.30 – 15.00 LUNCH – INDUSTRY SATELLITE

15.00 – 16.00 Thematic unit 8. Living with a Chronic Disease: Implications for Life Phases

	Chairpersons: Goh Ai-Sim (Malaysia)	Speaker
15.00 – 15.20	The ageing patient	Farrukh Shah (UK)
15.20 – 15.40	Nutrition in Thalassaemia / SCD and other Rare Anaemias	Ellen Fung (USA)
15.40 – 16.00	Discussion	

16.00 – 17.15 Thematic unit 9. Curative approaches of thalassaemia and sickle cell disease

	Chairpersons: S. Hongeng (Thailand)	Speaker
16.00 – 16.20	Gene addition – where do we stand today?	
16.20 – 16.40	Gene editing: current developments	
16.40 – 17.00	Access to curative therapies – the patients perspective	
17.00 – 17.15	Discussion	

17.15 – 17.45 COFFEE BREAK

17.45 – 19.15 Thematic Unit 10. New scientific advances

17.45 – 18.05	Luspatercept in Transfusion and Non Transfusion Dependent Thalassaemia – the post-authorisation era	Speaker Antonio Piga (Italy)
18.05 – 18.25	Mitapivat for rare anaemias: what we know so far	MD Cappellini (Italy)
18.25 – 18.45	Innovative medications in pre-clinical and clinical development	Stefano Rivella (USA)
18.45 – 19.05	New therapies: a comparative approach	Khaled Musallam (UAE)
19.05 – 19.15	Discussion	

19.15 – 19.30 Closing Remarks by:

Conference Chairpersons:

- President Thalassaemia International Federation
- President, Malaysian Society of Haematology
- Vice-President, Malaysian Association of Paediatric Haematology & Oncology
- President, Malaysian Federation of Thalassaemia Societies

International Scientific Advisory Committee

International Patients Committee:

George Constantinou, TIF Board of Directors

~END OF DAY~