

Tuesday, 29 August 2023

**16<sup>th</sup> International Conference on Thalassaemia & Other  
Haemoglobinopathies  
&  
18<sup>th</sup> TIF Conference for Patients & Parents**

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

**Draft Scientific Programme**

Friday 3<sup>rd</sup> November 2023

**12.00 – 13.30 Regional Networks Meeting**  
Chairpersons: Veena Selvarathnam (Malaysia)

**15.00 – 17.00 CLINICAL MANAGEMENT EDUCATIONAL OVERVIEWS – TIF'S GUIDELINES**

*\*\*pre-registration required ; session will be provided ONLY if there is sufficient interest from participants\*\**

- Clinical Management of Transfusion Dependent Thalassaemia John Porter (UK)
- Clinical Management of Non-Transfusion Dependent Thalassaemia ( $\alpha$ -thalassaemia) Ali Amid (Canada)
- Clinical Management of Non-Transfusion Dependent Thalassaemia ( $\beta$ -Thalassaemia) Ali Taher (Lebanon)
- Clinical Management of Sickle Cell Disease – Children Baba Inusa (UK)
- Clinical Management of Sickle Cell Disease – Adults

**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)

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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 4<sup>th</sup> November 2023

**08.00 – 09.00 ORAL ABSTRACT PRESENTATIONS**

**08.15 – 09.00 INDUSTRY SATELLITE**

**09.00 – 09.30 HONORARY PRESENTATIONS**

09.00 – 09.15 Our host country: Thalassaemia in Malaysia Zulaiha Muda (Malaysia)

09.15 – 09.30 Reaching out to the community concerning awareness and prevention of thalassaemia across cultures globally

**09.30 – 10.45 Thematic unit 1. Inequalities in the provision of care**

Chairpersons: ~~TBC~~ [S. Fucharoen](#) Speaker  
09.30 – 09.50 Addressing inequality in Haemoglobin Disorders  
09.50 – 10.10 Addressing sustainability & resilience of healthcare systems: George Pantelides (Cyprus) & Eleana Christoforou (Cyprus)  
The contribution of chronic, hereditary diseases  
10.10 – 10.30 Productive advocacy: capacity building for addressing health John James (UK)  
authorities  
10.30 – 10.45 Discussion

**10.45 – 11.15 COFFEE BREAK**

**11.15 – 12.30 Thematic unit 2. Pathophysiology impacting clinical developments**

Speaker  
11.15 – 11.35 Erythroid Maturation  
11.35 – 11.55 Genetic modifiers of thalassaemia phenotype and new therapies  
11.55 – 12.15 Iron metabolism and the hepcidin cascade in thalassaemia Stefano Rivella (USA)  
12.15 – 12.30 Discussion

**12.30 – 14.00 LUNCH – INDUSTRY SATELLITE**

**14.00 – 15.30 Thematic unit 3. Providing optimum care to patients**

14.00 – 14.20	Hematologic and iron parameters as prognostic markers of outcomes in beta-thalassemia	Khaled Mussalam (UAE)
14.20 – 14.40	Challenges in Transition from Childhood to Adult clinics	Farzana Sayani (USA)
14.40 – 15.00	Novel insights and guidelines for the management of Non-Transfusion Dependent Thalassemia (NTDT)	Ali Taher (Lebanon)
15.00 – 15.15	TIF's Educational Programme for Healthcare Professionals: its impact and contribution	Dimitris Farmakis (Greece)
15.15 – 15.30	Discussion	

**15.30 – 16.00 COFFEE BREAK**

**16.00 – 17.00 Thematic unit 4. Alpha thalassaemia**

16.00 – 16.15	Chairpersons: Chi-Kong Li (Hong Kong) & Vip Viprakasit (Thailand) Accurate diagnosis of $\alpha$ -thalassaemia	Speaker Pimlak Charoenkwan (Thailand)
16.15 – 16.40	HbH disease – the clinical spectrum	Ali Amid (Canada)
16.40 – 17.00	Discussion	

**17.00 – 18.15 Thematic unit 5. Sickle cell disease**

17.00 – 17.20	New therapies for the care of sickle cell disease	Speaker John Porter (UK)
17.20 – 17.40	Pain management	Baba Inusa (UK)
17.40 – 18.00	Haemoglobin Disorders in the Emergency Department	
18.00 – 18.15	Discussion	

**18.15 – 19.15 PARALLEL INDUSTRY SATELLITE**

**18.15 – 19.15 ORAL ABSTRACT PRESENTATIONS**

~END OF DAY~

Sunday 5<sup>th</sup> November 2023

**\*\* Joint with Patients/Parents \*\***

### **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 $\beta$ -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~**