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
ASEAN (TBC)
WHO Representative to Malaysia, Brunei Darussalam and Singapore - Dr Rabinra Abeyasinghe,

(on behalf of WHO West Pacific Regional Office Director)
Malaysian Haematology Society
Malaysian Association for Paediatric Haematology & Oncology
Federation of Malaysian Thalassaemia Societies
Mr Panos Englezos, President of the Thalassaemia International Federation

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

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 thalasasemia – 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

10.45 – 12.30 TIF General Assembly

Moderator: A. Eleftheriou

- Report of 2018 – 2023 by the President:
  o Activities
  o 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

Speaker

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
Discussion

12.30 – 14.00 LUNCH

1 Only representatives of TIF Members (Full and General) can participate
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
- UN Human Rights Special Rapporteur
- WHO - Rabindra Abeyasinghe (WHO Representative to Malaysia, Brunei Darussalam and Singapore)
- UNESCO Chair in Human Genetics on Thalassaemia, Universiti Sains Malaysia
- ISBT
- EHA
- ICER
- 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~
** Joint with Patients/Parents **

### Thematic unit 6. Challenges in service provision

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<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Chairpersons</th>
<th>Speaker</th>
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<tbody>
<tr>
<td>09.00 – 09.20</td>
<td>Quality and safety of blood: where are we?</td>
<td>TBC &amp; TBC</td>
<td>Androulla Eleftheriou (Cyprus)</td>
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<tr>
<td>09.20 – 09.40</td>
<td>Availability and accessibility of iron chelation drugs: Challenges</td>
<td>TBC &amp; TBC</td>
<td>Androulla Eleftheriou (Cyprus)</td>
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<tr>
<td>09.40 – 10.00</td>
<td>Quality standards for treatment centres and the need for Reference Centres and MDC</td>
<td>TBC &amp; TBC</td>
<td>Androulla Eleftheriou (Cyprus)</td>
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<tr>
<td>10.00 – 10.15</td>
<td>Discussion</td>
<td>TBC &amp; TBC</td>
<td>Androulla Eleftheriou (Cyprus)</td>
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<thead>
<tr>
<th>Time</th>
<th>Round-Table Discussion Quality of Life Measurements: Meaningful interpretations</th>
<th>Medical Perspective:</th>
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<tbody>
<tr>
<td>10.15 – 11.00</td>
<td></td>
<td>Yesim Aydinok (Turkey)</td>
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<td></td>
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<td>Patient Perspective: Veeresh Pavate (Canada) &amp; TBC</td>
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### Thematic unit 7. Complications of β-thalassaemia

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<tr>
<td>11.30 – 11.50</td>
<td>Heart disease: What is new?</td>
<td>TBC &amp; Ong Gek-Bee (Malaysia)</td>
<td>D. Farmakis (Greece)</td>
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<tr>
<td>11.50 – 12.10</td>
<td>Liver disease: early diagnosis and treatment</td>
<td>TBC &amp; Ong Gek-Bee (Malaysia)</td>
<td>MD Cappellini (Italy)</td>
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<tr>
<td>12.10 – 12.30</td>
<td>Malignancies in beta thalassaemia</td>
<td>TBC &amp; Ong Gek-Bee (Malaysia)</td>
<td>Ali Taher (Lebanon)</td>
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<tr>
<td>12.30 – 12.50</td>
<td>Bone disease: how to prevent bone pain and complications</td>
<td>TBC &amp; Ong Gek-Bee (Malaysia)</td>
<td>Ali Taher (Lebanon)</td>
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<tr>
<td>12.50 – 13.10</td>
<td>Endocrinopathies</td>
<td>TBC &amp; Ong Gek-Bee (Malaysia)</td>
<td>Ali Taher (Lebanon)</td>
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<tr>
<td>13.10 – 13.30</td>
<td>Discussion</td>
<td>TBC &amp; Ong Gek-Bee (Malaysia)</td>
<td>Ali Taher (Lebanon)</td>
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### Thematic unit 8. Living with a Chronic Disease: Implications for Life Phases

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<tbody>
<tr>
<td>15.00 – 15.20</td>
<td>The ageing patient</td>
<td>TBC &amp; Goh Ai-Sim (Malaysia)</td>
<td>Farrukh Shah (UK)</td>
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<tr>
<td>15.20 – 15.40</td>
<td>Nutrition in Thalassaemia / SCD and other Rare Anaemias</td>
<td>TBC &amp; Goh Ai-Sim (Malaysia)</td>
<td>Farrukh Shah (UK)</td>
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<tr>
<td>15.40 – 16.00</td>
<td>Discussion</td>
<td>TBC &amp; Goh Ai-Sim (Malaysia)</td>
<td>Farrukh Shah (UK)</td>
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### Thematic unit 9. Curative approaches of thalassaemia and sickle cell disease

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<th>Time</th>
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<tbody>
<tr>
<td>16.00 – 16.20</td>
<td>Gene addition – where do we stand today?</td>
<td>TBC &amp; S. Hongeng (Thailand)</td>
<td>Farrukh Shah (UK)</td>
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<tr>
<td>16.40 – 17.00</td>
<td>Access to curative therapies – the patients perspective</td>
<td>TBC &amp; S. Hongeng (Thailand)</td>
<td>Farrukh Shah (UK)</td>
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COFFEE BREAK

LUNCH – INDUSTRY SATELLITE

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17.00 – 17.15  Discussion

17.15 – 17.45  **COFFEE BREAK**

17.45 – 19.15  **Thematic Unit 10. New therapeutic approaches**

<table>
<thead>
<tr>
<th>Time</th>
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| 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  
Speaker: MD Cappellini (Italy) |
| 18.25 – 18.45 | Innovative medications in pre-clinical and clinical development  
Speaker: Stefano Rivella (USA) |
| 18.45 – 19.05 | New therapies: a comparative approach  
Speaker: 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:**
TBC

**International Patients Committee:**
TBC

~END OF DAY~