

Friday, 14 July 2017

## 16th TIF International Conference for Patients & Parents

17 – 19 November 2017

Thessaloniki, Greece

Friday 17<sup>th</sup> November 2017 // **Hall TBC**

15.00 – 17.00 TIF Board Meeting *\*\*by invitation only\*\**

### OPENING CEREMONY

#### *Master of Ceremonies:*

- 18.00 – 19.00 Opening remarks  
19.00 – 19.15 TIF Award Ceremony

### KEYNOTE PRESENTATIONS

#### Chairpersons:

- 19.15 – 19.30 Haemoglobinopathies Care & Cure: Have we reached the end?  
19.30 – 19.45 Migration: The aftershocks to the provision of healthcare  
19.45 – 20.00 Patients' as Equal Partners in Decision-Making: The Global Reality

Saturday 18<sup>th</sup> November 2017 // **Hall TBC**

09.30 – 10.00 **Session: International Initiatives**  
Chairpersons:

- 09.30 – 09.40 Greece: Pigi Zois  
09.40 – 09.50 China: Silk Road  
09.50 – 10.00 Pakistan: Bait-UI-Mal

10.15 – 13.00 **\*\* Common with Scientific Programme\*\***

10.15 – 11.30 **Session 2: Cornerstones of Clinical Management of Haemoglobinopathies**  
Chairpersons:

- 10.15 – 10.30 Optimal Blood Transfusion Therapy in Haemoglobinopathies

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**Coffee & Lunch will be available in Lobby Area at designated times on 18 & 19 November 2017.**

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10.30 – 10.45	Iron Overload & Chelation in Haemoglobinopathies
10.45 – 11.00	Multidisciplinary Care: the UK Experience
11.00 – 11.15	Best practices in assessing iron overload today: A need for Guidelines?
11.15 – 11.30	Discussion
<b>11.30 – 13.00</b>	<b>Session 3: Managing Complications in Haemoglobin Disorders – New Advances (I)</b> Chairpersons:
11.30 – 11.50	Endocrine complications
11.50 – 12.10	Cardiac complications
12.10 – 12.30	Liver complications
12.30 – 12.50	Renal complications
12.50 – 13.00	Discussion

**13.15 – 15.00 TIF General Assembly & Elections** *{Lunch will be provided}*

**15.00 – 16.00 Capacity Building of National Thalassaemia Associations**  
Moderators:

15.00 – 15.10 Brief Introduction by Moderators

15.10 – 15.45 Breakout Group Discussions

Table I: Fund-raising

Table II: Is thalassaemia a disability?

Table III: Working with Government

Table IV: Transition from Childhood to Adolescence and Adulthood

Table V: Psychosocial

15.45 – 16.00 Presentation of Conclusions by Breakout Groups

16.00 -16.10 Strategies in Communications

16.10 – 16.20 Safety & Efficacy of Drugs: What do I need to know?

16.20 – 16.30 Discussion

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**16.30 – 17.00**     **Session: The role of the Nurse in the Haemoglobinopathy Clinic**

**17.00 – 17.30**     **Session: The Digital Era of TIF**

Chairpersons:

17.00 – 17.15     TIF's Patient Connect Project

17.15 – 17.30     Electronic Educational Platform

**17.30 – 18.30**     **TIF Board Meeting** *\*\*by invitation only\*\**

*Sunday 19<sup>th</sup> November 2017 // **Hall TBC***

**09.30 – 10.30**     **Q&A with Experts**

**10.30 – 13.15**     **\*\*Common with Scientific Programme\*\***

**10.30 – 11.00**     **Session 8: Quality of Life in Patients with Haemoglobin Disorders**

Chairpersons:

10.30 – 10.40     Quality of Life: Transfusion Dependent Thalassaemia vs Non-Transfusion Dependent Thalassaemia

10.40 – 10.50     Moving towards Patient Reported Outcomes

10.50 – 11.00     Discussion

**11.15 – 12.45**     **Session 9: New Advances in Haemoglobinopathies**

Chairpersons:

11.15 – 11.45     The changing face of Management: Latest update of on-going clinical trials

11.45 – 12.00     Advances in Gene Therapy Trials

12.00 – 12.15     Treatment of Liver Disease: New developments

12.15 – 12.30     Gene Editing – *B. Lundberg*

12.30 – 12.50     *Topic to be Announced*

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12.50 – 13.00 Discussion

13.00 – 13.15 Closing remarks

13.15 – 14.00 **LUNCH**

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