

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? – *J. Porter*  
19.30 – 19.45 Migration: The aftershocks to the provision of healthcare – *S. Lobitz*  
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: **TBC**

- 09.30 – 09.40 Greece: Pigi Zois – *V. Perifanis*  
09.40 – 09.50 China: Silk Road – **TBC**  
09.50 – 10.00 Pakistan: Bait-UI-Mal – **TBC**

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 – *J. Porter*

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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 – <i>A. Taher</i>
10.45 – 11.00	Multidisciplinary Care: the UK Experience – <i>P. Eleftheriou</i>
11.00 – 11.15	Best practices in assessing iron overload today: A need for Guidelines? – <i>V. Viprakit</i>
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 – <i>V. de Sanctis</i>
11.50 – 12.10	Cardiac complications – <i>M. Walker</i>
12.10 – 12.30	Liver complications
12.30 – 12.50	Renal complications – <i>A. Taher</i>
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: L. Cannon & TBC

15.00 – 15.10 Brief Introduction by Moderators

15.10 – 15.45 Breakout Group Discussions

Table I: Fund-raising – Coordinators: M. Hadjidemetriou & H. Zivras

Table II: Is thalassaemia a disability? – Coordinator: A. Skafi

Table III: Working with Government – Coordinators: S. Tuli & E. Mylona

Table IV: Transition from Childhood to Adolescence and Adulthood – Coordinator: TBC

Table V: Psychosocial – Coordinator: S. Mina & E. Tsamadou

15.45 – 16.00 Presentation of Conclusions by Breakout Groups

16.00 -16.10 Strategies in Communications – *M. Hadjidemetriou*

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

16.20 – 16.30 Discussion

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- 16.30 – 17.00**    **Session: The role of the Nurse in the Haemoglobinopathy Clinic – TBC**
- 17.00 – 17.30**    **Session: The Digital Era of TIF**  
Chairpersons: R. Elbard & N. Gupta
- 17.00 – 17.15    TIF's Patient Connect Project – *A. Skafi*  
17.15 – 17.30    Electronic Educational Platform – *V. Antoniadou*
- 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**

Coordinator: A. Eleftheriou

Panelists: J. Porter, A. Taher, M.D. Cappellini, A. Piga, V. de Sanctis, M. Walker, V. Viprakit

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

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

Chairpersons: R. Elbard & G. Theophanous

10.30 – 10.40    Quality of Life: Transfusion Dependent Thalassaemia vs Non-Transfusion Dependent Thalassaemia – *M. Karimi*

10.40 – 10.50    Moving towards Patient Reported Outcomes – *V. Viprakit*

10.50 – 11.00    Discussion

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

Chairpersons: D. Kountouras & E. Yannaki

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

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*

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12.30 – 12.50	<b>TBC</b>
12.50 – 13.00	Discussion
<b>13.00 – 13.15</b>	Closing remarks <i>P. Englezos, V. Dimos, C. Papageorgiou, S. Tuli, R. Ficarra</i>
<b>13.15 – 14.00</b>	<b>LUNCH</b>