



Attendance Report

European Hematology Association Annual Congress



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**WP5 / T5.1 : Participation of TIF
experts in scientific conferences**

The Thalassaemia International Federation (TIF) has successfully participated in the 28th EHA Annual Congress, held this year in a hybrid format between 08-11 June 2023 in Frankfurt, Germany. Additional virtual days were organized on 14 – 15 June 2023.

Mr Loris Brunetta (TIF Board Member) and Mrs Lily Cannon (TIF Deputy Director) represented the Federation in Frankfurt participating in a number of sessions. In addition, TIF's educational material was distributed at the Patient Advocacy Hub, an exhibition booth for the EHA Patient Advocacy Group (EHA-PAG).



The TIF Delegates attended among others:

- 2 satellite symposia focusing on the new scientific advances in thalassaemia and other rare anaemias;
- HA – Patient Joint Symposium sessions focussing on making clinical trials more patient-centred and the importance of early dialogue with stakeholders;
- A session on Patient Blood Management: From WHO policy to practical applications
- Numerous oral presentations and poster sessions that provided ample information on the progress of newly approved therapies and those still in clinical trials.



Virtual Days of the 28th EHA Annual Congress, held on 14 and 15 June 2023.

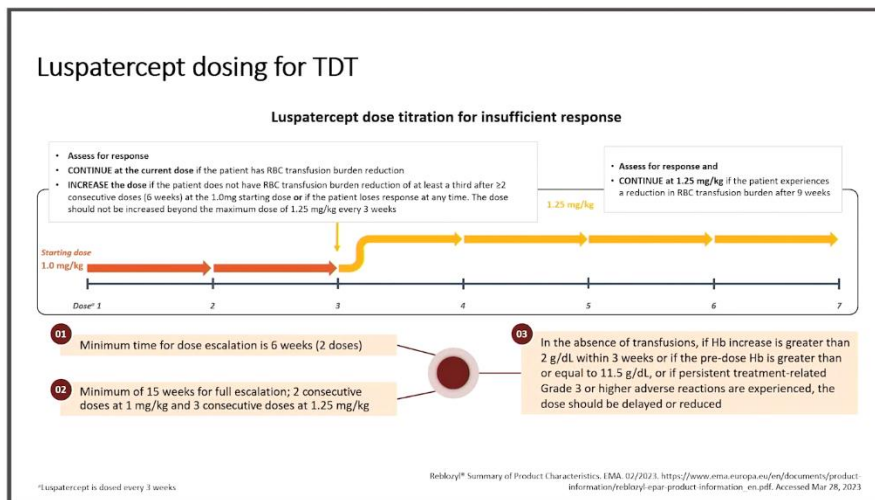
- Dr Androulla Eleftheriou (TIF Executive Director), Dr Michael Angastiniotis (TIF Medical Advisor) and Ms Lily Cannon (TIF Deputy Director) have attended a satellite symposium

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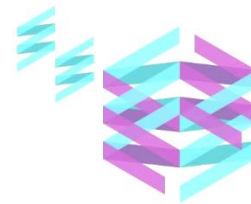
entitled “Management of β -thalassaemia in 2023: Where are we now?” held on 14 June 2023.

The eminent speakers of the symposium, Prof. MD Cappellini (Italy) and Prof. Ali Taher (Lebanon) presented case studies of transfusion-dependent (TDT) and non-transfusion dependent thalassaemia (NTDT) describing the patient journey, transfusion requirements, complications and available novel therapies. The discussion, chaired by Prof. Dr. Holger Cario (Germany), provided an opportunity for Prof. Taher to highlight the updates in the clinical management of NTDTs as described in the NTDT Guidelines recently published by TIF and co-authored by Prof. Cappellini, Dr Khaled Musallam and himself.

Transfusion-dependent β -thalassaemia: The Patient Journey



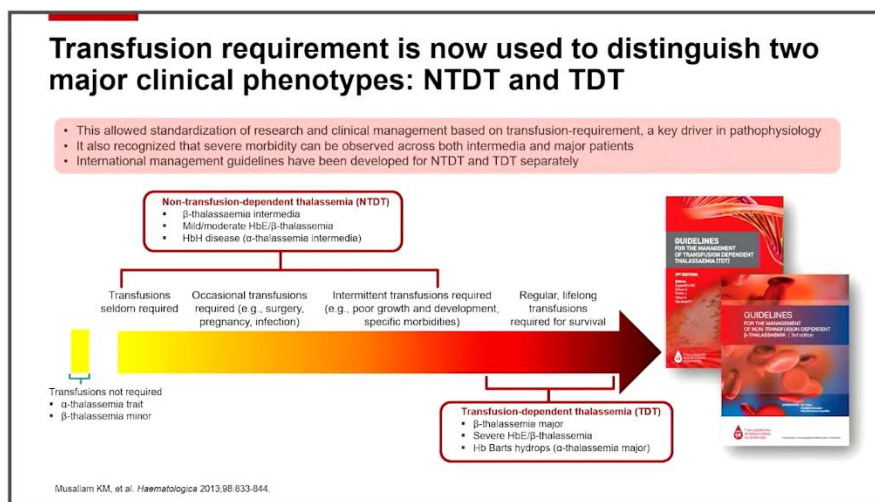
Maria Domenica Cappellini
University of Milan,
Ca' Granda Foundation IRCCS Maggiore
Policlinico Hospital, Italy



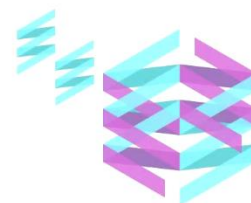
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Non-transfusion-dependent β -thalassaemia: From Trials to Practice



Ali Taher
American University of Beirut,
Lebanon



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- Mr Panos Englezos (TIF President), Dr Androulla Eleftheriou (TIF Executive Director), Dr Michael Angastiniotis (TIF Medical Advisor) and Ms Lily Cannon (TIF Deputy Director) attended the EHA – EMA Joint Symposium entitled “Regulators, Clinicians and Data” held on 15 June 2023.

The Symposium, co-organised by the European Hematology Association (EHA) and the European Medicines Agency (EMA) brought together haematologists, HTA representatives, patients and industry to discuss meaningful data collection along the drug development and authorisation process, including clinical trials and regulatory approval. The patient perspective was represented by Mr Loris Brunetta, TIF Board Member and expert in regulatory affairs at the European level.

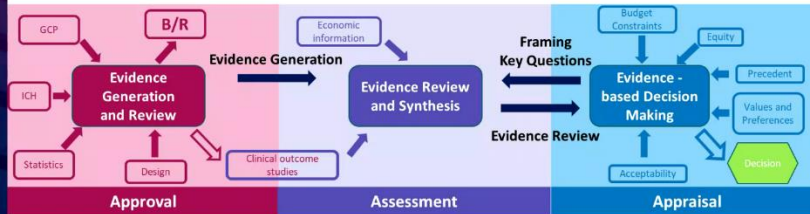
The discussion highlighted the importance of patient participation at all stages of trial development and assessment, and the promotion of more transparency by regulatory authorities, including health technology assessment (HTA) agencies, regarding their methodology and level of patient involvement. Indeed, strides forward have been made by the newly adopted EU HTA Regulation, to be implemented in 2025, making the inclusion of the patient voice mandatory in all its provisions.

TIF has been selected as one of a handful of patient organisations to be a full member of the HTA Stakeholder Network, appointed by the European Commission to support the Member State Coordination Group. The first meeting of the Network has taken place on 14 June 2023 in Brussels with TIF participation.



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Can decisions have unwanted consequences?



Adapted from Teutsch, S.; Berger, M. (2005) 'Evidence synthesis and evidence-based decision making: Related but distinct processes. *Medical Decision Making*, pp 487-489



Anja Schiel

Multi-stakeholder panel on data generation for regulatory purposes - HTA representative

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