



THALASSAEMIA INTERNATIONAL FEDERATION (TIF)

14th International Conference
on Thalassaemia and Other Haemoglobinopathies
& 16th TIF Conference for Patients and Parents

17-19 November 2017 • Grand Hotel Palace, Thessaloniki, Greece

PRESIDENT'S ADDRESS OPENING CEREMONY

17 November 2017

18.00-20.00

Your Excellencies, distinguished guests,

Welcome to the joint 14th International Conference on Thalassaemia and Other Haemoglobinopathies for Healthcare Professionals, and the 16th TIF Conference for Patients and Parents.

This International Conference constitutes the largest educational event of the Thalassaemia International Federation (TIF) and this

year we are delighted to have organized it in the beautiful city of Thessaloniki, in collaboration with the Greek Thalassaemia Federation (EOTHA), and with the support of both the Greek Thalassaemia Association (ESTHA) and the Hellenic Society of Haematology. Moreover, we feel extremely privileged to have set this conference under the auspices of the Greek Ministry of Health, with the participation of the Hellenic Center for Disease Control & Prevention and the city of Thessaloniki with all the support and warmth offered by the honourable Mayor, Mr. Boutaris.

Organized in the context of TIF's internationally renowned Educational Programme, this event is expected to congregate more than 1000 of the most important actors in the field of thalassaemia and other haemoglobinopathies, namely healthcare professionals across medical and scientific specialisations, patients/parents, and the industry from over 54 countries of the world.

In addition to patient empowerment and capacity building, which are key features of TIF's work, this conference will cover a broad range of topics on thalassaemia prevention, clinical management and multidisciplinary care, and, very importantly, the topic of the new advances in the areas of care and cure for thalassaemia and other haemoglobinopathies. It is thus expected to provide a unique forum for sharing knowledge and experience, for building collaborations and networks, and for strengthening existing ones. As we strive towards the achievement, by 2030, of the new set of goals set by the United Nations and the World Health Organisation, the promotion of patient involvement and ensuring that patient-centeredness in healthcare systems remain important and indispensable targets for TIF.

It is not by chance that Greece was chosen to host today's event. Greece has played an integral part in the history of thalassaemia, and was amongst the founding countries of TIF, both through its

dynamic patient community but also through its dedicated medical community, which has contributed immensely to achieving a better understanding of the pathophysiology and the complex clinical outcomes of the genetic defect, and subsequently a better understanding of the elements that are essential for its effective control and management. Many Greek names feature in the international literature, both in the early years, turning dark paths into lit avenues, but also in more recent years by sharing their great success in prevention and control, and research activities with the world, hence providing invaluable information, expertise and knowledge for others to build on.

TIF is greatly indebted to its distinguished Greek collaborators and advisors, but its gratitude extends to all eminent members of its International Advisory Panel who have all with sincere passion and undivided commitment supported TIF's work from the beginning of its establishment, particularly in the context of its

Educational Programme, which has had a measurable impact globally.

Understandably, there is still a long way to go considering the huge heterogeneity that exists in the adoption of appropriate policies to effectively control these genetic disorders and bridge the consequent gaps in the equity of patients' access to quality health- and other care.

At the same time, science has made and continues to make great advances in meeting patients' expectations in terms of ensuring both health and quality of life. It is TIF's, and every other stakeholder's, responsibility to work with the World Health Organisation, Regional decision-making bodies and national governments to ensure that these advances become available, accessible and officially adopted by all countries for the benefit of all patients wherever they may live. TIF is moving ahead with new targets and new tools but always with the same vision, and

following the same mission, which is precisely to establish EQUAL ACCESS to quality and approved health and other care for all patients, wherever they may live through nationally coordinated and supported programmes for thalassaemia control and management.

The beautiful city of Thessaloniki, the host city of this Conference is named after the half-sister of Alexander the Great, and is located in the heart of Macedonia and the second largest city in Greece. A city with an unbroken 3,000-year-old history, each footstep will reveal a small treasure to you! Discover the relics of its Roman, Byzantine, Ottoman past and of its formerly dominant Jewish population. Enjoy an entire district filled with Byzantine churches that are included in UNESCO's World Heritage list; Feast on its diverse and multicultural cuisine with influences from the East; Taste its famous sweet delicacies; Meet the locals famed for their warmth and open-heartedness. Rich in history and culture, Thessaloniki constitutes a unique mosaic of different

cultures and civilizations and a destination that you will definitely fall in love with!

Allow us to thank each and all of you for honouring us with your presence and express our deepest appreciation to the entire Faculty for their unwavering dedication and invaluable contribution and of course to the patients/parents community for their immense interest to attend this Conference.

This year's requests to participate in the Conference from the patients/parents community have come in masses from all over the world and have exceeded our expectations. This has been an incredible experience for us and we are terribly saddened to have had to turn down several requests. However, receiving this interest has been the best reward to us for our work, demonstrating the impact that TIF has had across the world, but also bringing to us the realization that we have an even greater responsibility to advocate for the implementation of policies that

will safeguard and ensure a better quality of life for every patient in every country of the world, and to terminate any violation of their human rights.

We hope that the programme will meet the highest of your expectations, and will, with your help and suggestions, become better.

This historic event will serve as a stepping-stone to jointly build a brighter future for patients with haemoglobinopathies.