



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

CLOSING REMARKS

19th November 2017, 13:00 – 13:30

Grand Hotel Palace, Thessaloniki, Greece

PRESIDENT'S MESSAGE

Distinguished guests,

Dear friends

It is with great pleasure and immense satisfaction that I have witnessed the interest and enthusiasm for participation and contribution of both the health care professionals and the patient/parents participating the 14th and the 16th International Conferences respectively in sharing information and experiences, in establishing collaborations and promoting networks and in expressing interest to participate in projects.

The International Conferences indeed still constitute the best and truly unique events and fora for keeping everyone well updated, reliably informed, actively involved on advances in all areas of prevention, care and cure and for strengthening existing collaborations while making new ones.

The expression of interest of hundreds of patients and doctors - well beyond our expectations - to attend and contribute to these, demonstrate that such educational fora are still needed and very much wanted while at the same time it demonstrates and underscores the confidence and trust that they have placed on TIF's work.

This is the biggest reward for TIF and an evidence for all of us volunteers working with TIF in that our efforts and hard work have indeed contributed in creating strong and reliable opportunities for all involved, health care professionals, patients/parents and the community at large for learning, sharing and collaborating.

This success means greatly for me as a parent of a thalassaemia patient whom I've lost in 1993.

But I am still motivated and empowered to continue working hoping that I am contributing even to a small extend to global improvements and for a better, brighter future for all patients.

The vast expression of interest to participate in these conferences, is indeed the best reflection of the great and sincere appreciation of the global health care professionals' and patients' communities to the work of TIF.

At the same time, such expressed trust and confidence place a considerably heavy obligation on our shoulders to safeguard that what has been achieved after longterm and extremely hard work, will not only continue to happen but moreover will strengthen even further our work as we strive towards the achievement of our mission: equal access to quality heath and other care for all thalassaemia patients wherever they may live.

Today we can safely state, and the programme of the conferences confirms so, that thalassaemia is no longer a fatal, child disease.

It has an open ended survival with high quality of life when appropriate policies and guidelines on the management and prevention are adopted and adhered to under national coordination and with sincere political commitment.

No chronic disease in no country, however affluent it may be, can be successfully and holistically addressed unless there is true political commitment and national coordination of a disease specific strategy encompassing both pillars of prevention and patient health and other care.

These conferences have acknowledged the huge scientific and academic advances that have cumulated in the last decades while they have highlighted the many that we are truly privileged to know that are in the pipeline.

Advances that will uplift the health and quality of life of our patients.

Advances that will write a new historical turn of the core of this disease.

Advances that need to become accessible and available to every patient, to all patients and not only to those privileged ones that live in countries with robust health infrastructure and national health care systems that historically offer universal coverage and quality health and social services.

TIF has been created to ensure progress in research, to ensure adoption of quality standards of care and effective prevention.

Having the patient in the centre of policies and with the patient's active involvement and participation in all reforms, changes and advances remains however a key focus of our work.

TIF remains committed to supporting the needs of those patients in the less fortunate, developing countries with no framed national health care system and is fully committed moreover to exert every effort to ensure that these systems are developed in a patient-centered way to serve the patient and to include the patient's perspective in the decisions taken.

These constitute key elements of TIF's work and I am very proud to see the fruits of our efforts in this direction as well and very much so in the context of these two international conferences' programmes.

The ongoing expansion of our patient advocates and our patient experts group around the world having a substantial role and active participation in what is happening around them and for them at their country level and beyond is for TIF a truly impressive progress and a great achievement.

A lot of our patients are now experts in their disease management, in knowing and advocating for their rights and in fighting for improvements and for a better future.

I am delighted to observe the participation of patients in this conference as well even more strengthened and their active role and position in the programme.

What a change! What a remarkable change of roles and environments, albeit we still have a long way to go.

Ending, I would like to thank each one of the faculty members for their time and interest to contribute to the materialisation of these conferences, all the scientists and doctors that are here reflecting their interest, devotion and commitment to help thalassaemia patients and without the work of whom TIF would have never achieved the level of success it enjoys today particularly with regards to its educational programme – a key activity of TIF with global positive measurable impact.

I am confident that all participants have gained knowledge and have experienced a unique experience but more importantly I am confident that patients have shared between them knowledge and experiences, have made new friends, and have of course experienced and lived the warmth and hospitality of the so characteristic culture and history of Greeks and more particularly of the beautiful city of Thessaloniki.

I look forward to welcome you all again in a future event. Wishing you all the best.