

**Opening Ceremony at the
2nd MEGMA Conference on Thalassaemia & other
Haemoglobinopathies,
11-12 November 2016, Amman, Jordan**

Address by Mr Panos Englezos

President of Thalassaemia International Federation

Your Excellencies,

Your Highness

Dear Members of the Board of Directors of Thalassaemia International
Federation,

Distinguished guests,

Ladies and Gentlemen,

Dear friends,

I am delighted and greatly honoured to welcome you all on behalf of the
Board of Directors of Thalassaemia International Federation, the
organiser of this educational event, to Amman Jordan and to the 2nd
Middle East, Gulf and Maghreb Region Conference.

I feel indeed blessed and extremely privileged for having been entrusted since 1985 to act in my capacity as President of the Board of TIF, on behalf of the global thalassaemia community to promote and safeguard the rights of every patient for equal and free access to quality health and other care irrespective of ethnicity, religion, culture and language.

Ladies and Gentlemen,

For me, thalassaemia and the promotion of its effective holistic care all over the world, has been and still is, a lifetime commitment.

The birth of my son George in 1968, marked the beginning of a lifelong journey with an unknown destination for me and my whole family.

Indeed, his birth structured and paved my way to a new world that had a totally different content, a new world where my commitments, priorities and work had a complete diversion of focus, as my whole life, began to be centered around my child and his disease.

A disease for which knowledge was poor and its future prospect even poorer.

It was fortunate that I had the opportunity to meet with many other patients and parents many of whom came on board this journey since the early days when we were all trying to understand better in our own countries in the early 1970s how to best help our children.

It was the time that small support groups began to develop in Cyprus and elsewhere aiming just and only to ameliorate our pain and desperation through sharing our concerns, our experiences, our problems and our fears and through learning from each other.

We are all aware today however, how these groups have expanded in numbers and objectives – how small patients/parents support groups have been gradually transformed into active NGOs and Federations working at the local and national level towards promoting and supporting the improvement of conditions and care of patients with thalassaemia.

Patients/ parents groups extended in scope, vision and mission.

The process towards achieving this was not easy.

It was long, difficult and required undivided commitment and multiple sacrifices with unpredictable consequences.

Fighting independent of, and when necessary against, health professionals and/or Government officials, required, and still does, true boldness and huge support from every member of the close and extended family.

When taking the decision to act on behalf of patients and parents, one knows that many aspects of your life come at stake, become jeopardised including your professional and social life and your personal wishes and targets are no longer a priority.

Promoting the health and quality of life of the patients becomes your first priority.

However, with full knowledge and recognition of the many challenges this journey may entail, I humbly declare today that I would not change my decision or passion if I had to do it from the beginning.

The progress that has been achieved in many countries including this Region did not happen as a result of Governments' decision to prioritize thalassaemia on national health agendas and this is with all due respect to Governments' and countries' health priority concerns.

Progress happened when patients and parents decided to take action and decided to take their fate into their hands.

Progress happened when patients/parents support groups, without infrastructure and clear objectives, turned from silent observers of their case and dependent on others, mainly doctors, into strong Associations with clear mission and vision and with its members gaining knowledge and experience on the disease, enough to know how and what to demand for bettering their health and quality of life.

Progress and success happened only in countries where patients and parents recognised the power of unity and the strength of knowledge.

It is an undisputable fact today that wherever patients/ parents united their voice and efforts and fought for changes, progress was inevitable to happen and the examples are many mainly in Europe but also quite impressive has been the case in this Region as well.

Today, and for some years now, the value of patients' involvement and collaboration in decision making have been well recognised by international health bodies and very importantly in the EU.

In Europe for example, the participation and contribution of patients is even safeguarded and ensured in many countries through specific legislations.

The inclusion and respect of the patients' perspective have become an indisputable and essential part of all official discussions at all levels of decision making, clearly recognising that such practices contribute significantly to building up patient-centered health care systems which is after all the goal of today's world.

Despite TIF's genuine and continuous efforts to support its members Patients' Associations in building capacity and competence and despite making an effort to educate its member patients to acquire knowledge and strength enabling them to have active, substantial and official involvement at all decision making bodies, this has not unfortunately happened to a desired level.

We need true patient advocates to have their voice and position truly heard and heard at the right level.

Dear friends, patients and parents in the audience

You still have a long way, you have a pivotal role to perform, you have a big responsibility to undertake for yourselves, your families and your societies.

The need to work as equal and productive partners with your Governments and health professionals is key to ensuring changes and achieve progress but this can only happen if patients are knowledgeable and can document their requests appropriately and are competent and committed enough to fight if and when necessary.

The World Health Organisation and the United Nations have long ago declared publicly the right of all for decent and appropriate health and other care and it has long published a plethora of resolutions including specific ones on the control of haemoglobin disorders with unfortunately very poor results and very confined application globally.

We therefore all need to demand for their materialisation and request from the WHO and member countries that these resolutions are respected and put into effect.

TIF has the knowledge, the vast experience but above all the responsibility and commitment to support and collaborate with each national patient association to reach this goal.

Ending allow me to express my gratitude on behalf of TIF to those Governments and health professionals that joined the fight for improving the control of thalassaemia in their country and have contributed to the level of success that is seen in many parts of this Region.

Dear friends,

The fight has certainly not come to an end.

We are still on board the journey we started back in the 1960s.

New advances in care and cure give us optimism and strength to continue and strengthen our efforts.

Allow me last to pay my gratitude and appreciation to the National Health Authorities in Jordan and to all the health professionals and patients/parents who made the organisation of this educational conference possible.

I wish you all a productive Conference and an enjoyable educational experience.

Thank you