

# THALASSAEMIA INTERNATIONAL FEDERATION

In official relations with the World Health Organization



## HEADQUARTERS

31 Ifigenias, 2007 Nicosia, Cyprus • P.O.Box 28807, 2083 Nicosia, Cyprus  
Tel.: +357 22 319 129, Fax: +357 22 314 552, E-mail: thalassaemia@cytanet.com.cy

## REGIONAL COMMITTEE FOR EUROPE - 70TH SESSION

Virtual session, 14–15 September 2020

## STATEMENT OF THALASSAEMIA INTERNATIONAL FEDERATION (TIF)

### Agenda Item 6.1 (c): “Mid-term evaluation of implementation of the Action Plan for the Prevention and Control of Noncommunicable Diseases in the WHO European Region 2016–2025 (resolution EUR/RC66/R11)”

Dear Chairperson, Distinguished Delegates, Ladies and Gentlemen,

The Thalassaemia International Federation, safeguarding the rights of the global thalassaemia patient community, welcomes the recognition of noncommunicable diseases as a health priority, now taking prevalence over infectious diseases and malnutrition.

Nonetheless, the issue of noncommunicable diseases has become synonymous with the most prevalent categories of cardiovascular diseases, diabetes, cancer and chronic respiratory diseases, and obesity, primarily because these are linked to common risk factors and are thus preventable. Even though it is recognised that children ‘can die from treatable conditions, other than the above (see WHA66/2013/REC/1, Annex 4), the whole policy revolves around the abovementioned adult conditions.

The Thalassaemia International Federation represents a group of chronic, hereditary disorders affecting the haemoglobin molecule, which are the commonest of a much wider group of chronic disorders, each one rare in itself but which as a whole affect a very large proportion of the population. These rare and chronic disorders are under the general title of birth defects and are given a secondary role in the existing policy.

Birth defects are in general underestimated, if we consider that there are between 7,000-8,000 diseases, most of which are congenital and chronic, affecting 6-8% of the population. This is not a negligible health burden when considering the chronicity and complexity of care that they require. There are well documented strategies which can address both the prevention and the management of these disorders but which are not included in health planning of most countries of the region. This despite WHO resolutions WHA 59.20 and EB118.R1 on haemoglobin disorders as well as WHA63.17 on Birth Defects.

Through this statement, we would like to urge Member States to:

**RECOGNISE** the need to revisit these disorders and to consider a separate disease-specific approach in planning health services;

**PROMOTE** separate policies from the major noncommunicable diseases, which are so far promoted in the WHO agenda for noncommunicable diseases.

Thank you for your attention.



THALASSAEMIA INTERNATIONAL FEDERATION  
is the 2015 WINNER of:  
• UNIVERSITY OF NICOSIA'S AWARD  
for its MOST NOTABLE SOCIAL CONTRIBUTION



THALASSAEMIA INTERNATIONAL FEDERATION  
is the 2015 WINNER of:  
• DR LEE JONG-WOOK MEMORIAL PRIZE  
for its OUTSTANDING CONTRIBUTION IN PUBLIC HEALTH

[www.thalassaemia.org.cy](http://www.thalassaemia.org.cy)

