

THALASSAEMIA INTERNATIONAL FEDERATION

In official relations with the World Health Organization



HEADQUARTERS

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Request to the Chairman of the 71st session of the WHO World Health Assembly 21-26 May 2018, Geneva, Switzerland

STATEMENT OF THALASSAEMIA INTERNATIONAL FEDERATION (TIF)

Agenda Item 11.5: “Addressing the global shortage of, and access to, medicines and vaccines”

Delivered by **Dr Victor BOULYJENKOV**, TIF-WHO Liaison Officer

Dear Chairperson, Distinguished Delegates, Ladies and Gentlemen,

Thalassaemia International Federation would like to stress, the huge unmet need of equal access to medicines and vaccines, for all patients with thalassaemia and other hemoglobinopathies.

Given the absence of national registries, the numbers of patients in each country are underestimated, which means that policy and budgeting are not based on true needs. In addition, an estimated 60,000 new affected births are added each year due to the absence of any plan for prevention. Life-long regular red-cell transfusions and iron chelation, along with multidisciplinary care have dramatically improved patients' survival over the decades, transforming thalassaemia from a fatal pediatric disease to a chronic condition. At the same time, long survival in some settings increases the numbers of patients needing treatment. Out-of-pocket expenses are the rule in most countries.

According to estimates, less than 12% of children born with thalassaemia worldwide are regularly transfused and only 40% of them receive proper iron chelation.

Additionally, because of frequent transfusions, thalassaemia patients are at high risk of blood-borne infections, including hepatitis, which also add to the need for medication with antiviral drugs.

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

ENSURE that all patients have access to quality medicines for iron chelation and treatment of hepatitis C, including all relevant vaccines;

ADVOCATE for the adoption by the pharmaceutical industry of the WHO fair-pricing approach to guarantee all patients' access to affordable quality iron chelators and antiviral drugs;

DEVELOP synergies to increase negotiating power for procuring medicines;

ENCOURAGE the production and procurement of safe and effective generic medicines.

Finally, we would like to reiterate our firm commitment to support all WHO efforts in increasing access to medicines.

Thank you for your attention.



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for its MOST NOTABLE SOCIAL CONTRIBUTION



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