THALASSAEMIA INTERNATIONAL FEDERATION
In official relations with the World Health Organization

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Request to the Chairman of the 67th session of the WHO Regional Committee for Europe
11–14 September 2017, Budapest, Hungary

STATEMENT OF THALASSAEMIA INTERNATIONAL FEDERATION (TIF)

By Mr. Radu Costin Ganescu

Agenda item 5(d): "Strengthening Member State collaboration on improving access to medicines in the WHO European Region"

Mr. Chairman, Distinguished Delegates, Ladies and Gentlemen,

Thalassaemia International Federation welcomes and endorses WHO's efforts in strengthening Member State collaboration on improving access to medicines in the WHO European Region, especially as regards to the promotion of affordable medicines and the elimination of substandard and falsified medical products.

Thalassaemia and sickle cell disease are among the world's most common genetic diseases and contribute hugely to the public health burden of affected countries. An estimated 7% of the global population carries an abnormal haemoglobin gene, including thalassaemia. In the European region, there are more than 53,000 patients with thalassaemia and sickle cell, millions of carriers and around 1,800 new affected births per year, while these numbers are alarmingly increasing due to migration and most importantly, the absence or lack of implementation of effective national prevention and treatment policies in many countries of the region.

Although the majority of thalassaemia patients living in the European region and more specifically in the European Union (EU) have access to appropriate -and nearly optimal- care, including life-long drug therapy and iron chelation therapy, following international guidelines, a number of countries outside the EU face significant challenges in accessing timely and appropriate drug therapy. In addition, thalassaemia patients are dependent on frequent blood transfusions and are thus at high risk of infection with transfusion-transmitted infections (TTIs), including the hepatitis viruses. As a result, 10-80% of patients, globally and in some parts of Europe, are HCV-positive, with increased risk of cirrhosis and hepatocellular carcinoma. All preventive measures adopted, such as HCV and HBV mandatory screening and HBV vaccination programmes, have significantly reduced new cases of infection in Europe but the majority of all patients remain infected and thus in need of anti-viral drugs.

Through this brief statement, TIF takes the opportunity to request from the Regional Committee for Europe to:

ENCOURAGE Member States to increase access of patients with transfusion-dependent haemoglobin disorders (including thalassaemia and sickle cell disease) to timely, appropriate and effective treatment for Hepatitis C (HCV);

ADVOCATE for the adoption of the WHO fair pricing model by pharmaceuticals in order to guarantee access to safe, available and affordable iron chelation drugs for all thalassaemia patients;

PROMOTE the development of synergies between Member States to increase their negotiating power for procuring new medicines and health technologies.

All above requests constitute the position and consensus of the Board of Directors of TIF and fall within the 63rd WHA and WHO Executive Board Resolutions on thalassaemia and other haemoglobin disorders (WHA63.2; WHA63.17; EB118.R1), adopted in May 2010 and 2006, respectively.

Finally, we would like to express our deepest appreciation for the ongoing productive collaboration between TIF and the World Health Organization (WHO) and reiterate our firm determination and commitment to support all WHO efforts in placing haemoglobinopathies on the top of the national health agendas of all countries of the European region.

TIF is a non-profit organisation dedicated to improving the quality of life and life expectancy for all patients with inherited congenital haemoglobinopathies, such as thalassaemia. TIF is comprised of 204 member associations from 62 countries and has been working in official relations with WHO since 1996.