THALASSAEMIA INTERNATIONAL FEDERATION

In official relations with the World Health Organization

HEADQUARTERS

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A Global Call for Solidarity, Unity and Cooperation in support of the World Health Organization

The Thalassaemia International Federation¹, working in official relations with the World Health Organization (WHO) since 1996 and representing the global thalassaemia community, expresses its grave concern over the announcement of the United States to suspend financial support for the WHO until completion of a review of the organisation's activities related to the COVID-19 pandemic.

Since 1948, the WHO is the only existing coordinating authority on international health issues, with a leading role in developing and promoting a great number of public health programmes in various fields, including, inter alia, blood safety and availability, blood transfusion safety, congenital anomalies, essential medicines, gene-based therapies, genomics, communicable and non-communicable diseases. For many decades, its work has been a source of reference and interest for all countries with high prevalence of thalassemia.

The eradication of smallpox, the near-eradication of polio, and the development of an Ebola vaccine are only a few of the WHO's public health achievements in its efforts to contain highly transmissible diseases. Therefore, it is not the time to either reduce its resources or create a dangerous political rhetoric against the only international body that currently coordinates the worldwide response to COVID-19.

Therefore, through this Global Call:

• We pledge for the provision of continuous support by all 194 WHO Member States to the operations of the WHO, which has been working for decades to defend the right of people to health by advocating for universal healthcare, monitoring public health risks, coordinating responses to health emergencies, promoting human health and well-being, providing technical assistance to countries, setting international health standards and guidelines, collecting data and providing an international platform for discussions on health issues.

¹ The Thalassaemia International Federation (TIF) is a patient-oriented non-profit, non-governmental umbrella federation, established in 1986 with Headquarters in Nicosia, Cyprus. TIF's mission is to help ensure equal access to quality health and other care for every patient with thalassemia and other haemoglobin disorders around the world. To-date membership boasts 232 members from 64 countries across the globe. TIF works in official relations with the World Health Organization (WHO) since 1996 and enjoys active consultative status with the United Nations Economic and Social Council (ECOSOC) since 2017. Moreover, it is a strategic partner of the European Commission under the Third Health Programme since 2018 and a member of the Patients and Consumers Working Party (PCWP) of the European Medicines Agency (EMA) since 2010. In 2019, TIF obtained a participatory status at the Council of Europe, as a Member of the Conference of International NGOs. Moreover, TIF was awarded, in the context of the 68th World Health Assembly in May 2015, the 'Dr Lee Jong-wook Memorial Prize' for its outstanding contribution to public health.



- We call for global solidarity, unity and cooperation as fighting a global pandemic requires international cooperation and reliance on science and data to find effective solutions. As all countries globally face the same invisible, raging enemy, there is no time for politics and no space for questioning WHO's response, in the absence of which humanity as a whole would be in imminent danger.
- We call the countries of the developed world to stand for low- and middle-income countries, where people struggle to have access to basic and decent health and other care. The COVID-19 pandemic has created unprecedented challenges that threaten the lives of millions of patients in these countries, including people with thalassaemia and sickle cell disease.
- We call all national health authorities to take all the necessary safety and prevention measures in their respective health establishments for the containment of the pandemic, as health-care workers currently are one of the greatest vulnerabilities of health-care systems.
- We support initiatives for the creation of a global solidarity fund for all the hardest-hit countries that would alleviate the intolerable burden of the pandemic.
- We invite governments to ensure that all patients, and especially the chronic ones, have uninterrupted access to care, as any change in their treatment would cost their very lives.

With a haemoglobin level below 9, thalassaemia patients are <u>in grave danger</u>. Quoting a patient from a developing country with high thalassaemia prevalence:

"On the 8th of March, the first COVID-19 patient was detected in my country. Government declared a nationwide lockdown from 22 March. I need to take transfusion two times a month. In my country, only some hospitals have capacity for packed cell blood transfusion. I am unable to move due to the lockdown, so I received whole blood transfusion yesterday, after 34 days, from an MSF primary health care. They don't allow transfusion for patients with thalassaemia, if their haemoglobin is more than 5. My haemoglobin was 7.1. Day by day Covid-19 cases are increasing and I don't know what will happen in future. All other patients outside the capital are unfortunately in the same situation."

THE TIME TO ACT IS NOW.

