

# THALASSAEMIA INTERNATIONAL FEDERATION

In official relations with the World Health Organization



## HEADQUARTERS

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## REGIONAL COMMITTEE FOR EUROPE - 70TH SESSION

Virtual session, 14–15 September 2020

## STATEMENT OF THALASSAEMIA INTERNATIONAL FEDERATION (TIF)

**Agenda Item 2 (a): “Address by the WHO Director-General: the state of health in the world, including lessons learned from the COVID-19 pandemic”**

Dear Chairperson, Distinguished Delegates, Ladies and Gentlemen,

The Thalassaemia International Federation (TIF) represents patients with haemoglobin disorders, including thalassaemia and sickle cell disease, in 64 countries, working to safeguard patients' rights and ensure their equal access to universal health and other care.

The COVID-19 pandemic has raised concerns over the **safety and vulnerability of chronic patients**, as the syndrome displays respiratory complications and affects patients with compromised immune systems (e.g. thalassaemia, sickle cell disease), causing life-threatening anaemic hypoxia. Given that frequent visits to healthcare facilities are mandatory for most chronic patients, including transfusion-dependent thalassaemia patients, there arises the question of effective safety measures across establishments to decrease their risk of infection.

To address these challenges and in alignment with WHO Guidelines, the Thalassaemia International Federation was one of the first patient groups to prepare material guiding people with haemoglobin disorders and their treating physicians on how to best protect themselves from the virus, paving the way for other disease groups to do the same.

Nonetheless, the **absence of disease-specific registries and patient records in most countries**, has not allowed TIF nor national health authorities to assess the level of impact of COVID-19 to chronic patients and proceed to targeted, evidence-based recommendations and measures. This would allow for the monitoring of patients' response to various therapeutic regimens, the duration of viral shedding, the complications that arise and the mortality in each disease category. **Such knowledge is not only important for the protection of vulnerable groups, but also for the development of effective treatments and vaccines.**

**We thus urge Member States to focus on disease-specific reporting and protect chronic patients from the spread and fatalities of the pandemic.**

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

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  
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