



## HEADQUARTERS

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## *Thalassaemia International Federation*

# **DECLARATION FOR ACCESS TO HEALTH AT THE TIME OF COVID-19 PANDEMIC**

The COVID-19 pandemic has sparked an unprecedented global crisis.

As it continues its spread across the world, to-date more than 47.5 million people have been infected in 190 countries and about 1.2 million people have lost their lives.

While waiting for a scientific miracle, the death toll is rising and so is the chaos of restrictions and lockdowns that have led the vast majority of countries to extended turmoil and severe economic regression.

Although Europe is currently seeing the steepest rise in new cases, the COVID-19 pandemic has sadly amplified the existing challenges faced by low- and middle- income countries.

Devoid of universal health coverage to-date, these countries host more than 80% of the global population affected by haemoglobin disorders, mainly thalassaemia and sickle cell disease.

These patients have been struggling for decades to acquire access to high-quality, equitable, affordable healthcare and to address their medical, social and other needs, but with very little success.

Unarguably, this pandemic has further deepened the division of a two-speed world and has deprived people with chronic, rare, and haemoglobin disorders of their basic right to health.

The COVID-19 has been proven to be life-threatening to all patients who rely on medical care and other public health resources, especially those suffering from transfusion-dependent and other multiple organ diseases, including thalassaemia and sickle cell



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disease and whose access to emergency care constitutes the cornerstone of their disease's management.

The voice of 10,000 individuals with haemoglobin disorders who responded to TIF's survey (March-June 2020) echoes the tragic consequences of the unsuccessful containment of the virus to-date and across the world, but mainly in countries with developing economies.

Already and prior to the pandemic, in these countries and regions of the world where more than 80% of patients with haemoglobin disorders are born and live:

- **64.8%** of patients with haemoglobin disorders did not have access or had interrupted access to transfusion therapy;
- **62.8%** received, inappropriately or sub-optimally processed, blood (RBCs);
- **Only 8.4%** had access or uninterrupted access to appropriate, for their needs, iron chelation treatment;
- **Only 4.8%** were provided with regular iron load monitoring and **even less (2.6%)** multidisciplinary care by experts from different medical disciplines.

The absence of universal coverage in the context of the healthcare systems in these countries added significantly to the confinement of patients' access to the necessary, for their disease, services.

The financial impact on the patients and their families was immense:

- **72.5%** of affected patients had to pay for access to a number of health services, including basic ones (e.g. transfusion in some countries). This withers financially both the patients and their families.

**The survey depicted that the COVID-19 pandemic has further amplified these challenges** by affecting the adequacy of blood with moderate to severe blood shortages in almost 90% (89.6%) of the patients and restricting their access to appropriate chelation and monitoring (86.5%).

Moreover, about 70% (68.7%) of the participants reported having restricted access to their treatment and more than 90% (91.8%) of those employed have lost their jobs and are now faced with psychological, social and financial repercussions.

If patients are left without continuity of care, their health and quality of life will be further deteriorated, with the prospect of higher mortality rates amongst this vulnerable group in the coming months.

**In light of** the above and in line with the United Nations Sustainable Development Goals (SDGs) 2030;

**In acknowledgment of** the triple billion targets of the World Health Organization (WHO);

**Recalling** relevant resolutions and/or recommendations and/or programmes of the WHO including those on thalassaemia, sickle cell disease, blood safety/adequacy, patient safety, Non Communicable Diseases (NCDs), congenital birth defects, access to innovative drugs and therapies, essential medicines list;

**Taking into account** that the comorbidities and the multi-organ nature of these disorders, their public health dependency and the severe impact of the pandemic on the economies of developing countries, where most patients live; and

**In view of** the evidence received from 10,000 affected patients in our member countries in the six regions of the world, as determined by the WHO;

**TIF calls upon all governments globally to:**

1. Accelerate their transition to Universal Health Coverage and address the existing health inequalities;
2. Reaffirm their commitment to provide continuity of care to all their citizens, including patients with haemoglobin disorders;
3. Implement all prudence and precautionary measures to protect the general population from the destructive effects of SARS-CoV-2;
4. Provide priority access to vaccines to all people with chronic and complex diseases, including those with haemoglobin disorders.

**No patient should be left behind**

*Panos Englezos*

*TIF President*