



# General Assembly

Distr.: General  
12 February 2024

English only

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**Human Rights Council**  
**Fifty-fourth session**  
11 September–13 October 2023  
Agenda item 6  
**Universal periodic review**

## **Written statement\* submitted by Iranian Thalassemia Society, a non-governmental organization in special consultative status**

The Secretary-General has received the following written statement which is circulated in accordance with Economic and Social Council resolution 1996/31.

[21 August 2023]

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\* Issued as received, in the language of submission only.



## The Universal Periodic Review Process in France

Iranian Thalassemia Society is a non-governmental organization aiming at improvement of medical care services and living standard of the thalassemia patients in the Islamic Republic of Iran. The organization does its best to provide the patients with medication, medical care and improve their quality of life. The Society which was established about 34 years ago is still completely reliant on charity donations.

Situation of Thalassemia Patients 23000 documented thalassemia patients live in the country. Since the banking system went under sanctions, no import company or distributor could work in the Islamic Republic of Iran anymore and access to medicine was seriously limited. In addition, the psychological back lash of sanctioning the Islamic Republic of Iran has made the European pharmaceutical companies refrain from selling medicine and medical equipment's to Iranians. Since the banking system went under sanctions, no import company or distributor could work in the Islamic Republic of Iran anymore and access to medicine was seriously limited. In addition, the psychological back lash of sanctioning the Islamic Republic of Iran has made the European pharmaceutical companies refrain from selling medicine and medical equipment's to Iranians.

This situation puts the most vulnerable people at higher risk; the poor people especially in the less developed provinces of Hormozgan and Baluchistan. These two the less developed provinces have more than half of the thalassemia patients of the country despite the widespread initiatives started by the organizations .

Several reports by the United Nations (UN), academia, non-governmental organizations [NGOs], and patient advocacy groups have addressed the potential adverse effects of sanctions on general population and specifically on the availability of medications in the Islamic Republic of Iran. They stated that sanctions have resulted in development of major difficulties for importing of not only finished products and pharmaceutical raw materials but also medical equipment needed in hospitals. Moreover, there are many reports of sanction-related deaths in the Islamic Republic of Iran due to drug supply shortage in patients with Thalassemia.

The Islamic Republic of Iran has a large population of thalassemia and congenital bleeding disorders with considerable burden on the health care system. Optimal care of these chronic diseases requires availability of specialized and disease-specific medical supplies and medications which are often quite expensive. As a result, these patients are amongst the most vulnerable to the possible shortage of medications and medical supplies. Thalassemia is an inherited blood disorder that causes the body to have less hemoglobin than normal. Hemoglobin enables red blood cells to carry oxygen. The disease afflicts people from birth and requires specialized medication to eliminate overload during blood transfusions.

The supply of required medications from the Swiss pharmaceutical group Novartis, which is the leading supplier, and key ingredients for these medicines produced by the French company Roquette Frères has been denied to the Islamic Republic of Iran.

Iranian thalassaemic patients are directly affected by the sanctions on medicine since 2018. 662 patients have lost their lives and more than 10,000 people have been seriously affected . Because of the sanctions, 70 thalassemia patients lost their lives in 2018, 90 in 2019, 140 in 2020, and 180 in 2021 .

Iranian Thalassemia Society has registered some recommendations to France to protest against this action. The text of the proposed recommendation for France during the fourth UPR report: "Given the negative effects of the unilateral coercive measures of the United States of America on the fundamental rights of Iranian patients (including the right to life and the right to health) and the over-compliance of some governments and private companies with the unilateral sanctions of the United States, Iranian Thalassemia Society, on behalf of 23,000 thalassemia major patients in Iran, asks the French government to ensure the observance of human rights, especially by pharmaceutical companies that are the exclusive suppliers of raw materials for thalassemia patients in the world (such as Rocket Company, registered in the territory of France) to ensure and prevent them from complying excessively with the unilateral and inhumane sanctions of the United States of America."

we highlighted that the sanctions have hindered the import of necessary medical equipment and supplies, including blood transfusion devices and medication, leading to serious health risks for thalassemia patients. thalassemia patients in the Islamic Republic of Iran were being penalized by over compliance with the United States of America sanctions against the country, which have reduced their access to vital medication from abroad. Companies involved in the process of supplying thalassemia medications have the responsibility to protect the human rights of patients in the Islamic Republic of Iran under the UN Guiding Principles on Business and Human Rights. The Sanctioning States have extraterritorial obligations to protect and not to violate human rights in other States. Accordingly, the UCM victim's harms should be addressed through compensation mechanisms and the OHCHR should start new initiative to help the victims to receive compensations.

### **Recommendations**

- We called on the states imposing the sanctions to consider the humanitarian consequences of their actions and to exempt medical equipment and supplies from the measures.
- We urge states to make sure that companies within their jurisdictions comply with their human rights obligations and ensure thalassemia patients in the Islamic Republic of Iran can access life-saving medicine.
- We also urge the international community to provide support to the Islamic Republic of Iran in addressing the impact of the sanctions on the health of its population, including thalassemia patients.

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<https://www.ohchr.org/en/press-releases/2023/02/iran-over-compliance-unilateral-sanctions-affects-thalassemia-patients-say>

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