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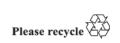
## **Human Rights Council**

Fifty-second session
27 February–31 March 2023
Agenda item 3
Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development

## 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.

[5 February 2023]





<sup>\*</sup> Issued as received, in the language of submission only.

## The Negative Impact Of Unilateral Coercive Measures on The Health Of Thalassemia Patients In The Islamic Republic Of Iran

Iranian Thalassemia Society, on behalf of the 2,300 thalassemia patients and their families, presents a statement regarding the impact of unilateral coercive measures on the right to health of these Iranian patients:

As the special rapporteur on the negative effects of unilateral coercive measures on the enjoyment of human rights stated in her recent report on her visit to the Islamic Republic of Iran to the 51st session of the Human Rights Council, the unilateral coercive sanctions have negatively affected the Iranian patients, especially those with thalassemia, in accessing appropriate medicines and medical devices. Since the withdrawal of the United States of America from the JCPOA, over 700 thalassemia patients have died due to drug shortages or no access to medicines such as Desefral vials or Gidneo tablets (manufactured by the Swiss company, Novartis) and another 8,000 patients also suffered numerous physical injuries, including diabetes and heart failure, and were at risk of death if the Iranian thalassemia community was not promptly provided with appropriate medical devices and medicines.

Prof. Dohan wrote: "Of particular concern are significant challenges and obstacles in procuring and delivery of life-saving medicines and medical devices to treat rare and severe diseases, including certain cancers, thalassemia, hemophilia, butterfly disease, multiple sclerosis, autism, and certain diabetes."

In 2021, Although importing oral medication was impossible, the Islamic Republic of Iran could import 1.5 million injectable doses for thalassemia patients out of the 10 million needed doses, resulting in a four-fold increase in mortality rate among those with thalassemia.

Prof. Douhan said that According to OFAC, medicine is supposed to be exempt from sanctions on humanitarian grounds. However, in practice, humanitarian exemptions for medicine appear ineffective and nearly non-existent due to the real or alleged fear of secondary sanctions, civil and criminal charges, reported "advice" not to do any business in the Islamic Republic of Iran, and the impossibility, complexity, uncertainty, and length of bank payments and good deliveries. This affects the whole scope of human rights of the Iranian people.

So, given that the right to access medicines and medical equipment is one of the fundamental human rights, the only demand of the Iranian thalassemia community is immediate access to medicines and equipment to survive and compensate the patients and their families for the losses. Meanwhile, the meaningful silence of some countries and Human Rights authorities about the disastrous death of patients in the Islamic Republic of Iran confirms their complicity in blatant crimes against humanity.

Iranian Thalassemia Society expresses its deep concern at such systematic injustice and urges the Council to lift the unilateral coercive measures against Iranian citizens as soon as possible so that special patients can enjoy their right to health and medical care. It should be mentioned that Iranian Thalassemia Society filed a complaint with the Human Rights Council in August 2021, which unfortunately has not been finalized yet, while Thalassemia patients in the Islamic Republic of Iran are suffering every day.

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