

# Chapters of the 10 Lives of Angels





## **Chapters of the Lives of 10 Angels**

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- Iran Autism Association
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# Chapters of the 10 Lives of Angels

The exhibition has an artistic look at the suffering and hope that 10 children patients experience through the constraints of access to medicine and medical equipment.

These restrictions made the artists join the human rights activists to raise international awareness on the negative effects of these restrictions on human rights.

For this reason, and being the voice of Iranian patients, the Organization for Defending Victims of Violence (ODVV), in collaboration with a number of artists, and NGOs holds an exhibition of photographs of Iranian patients suffering from medicine shortages during the 43rd session of the Human Rights Council.

The exhibition includes 10 real-life images of patients suffering from thalassemia, EB(Epidermolysis Bullosa), heart disease, autism, disability, cancer, and so on.

Organization for Defending Victims of Violence (ODVV) is a non-governmental, non-profit, non-political Organization in Special Consultative Status to the Economic and Social Council of the United Nations (ECOSOC). The ODVV was established in 1988 in Tehran and has been active in the field of human rights and humanitarian activities.

**Mahmoudreza Golshanpazhooh (Ph.D)**

**ODVV Director**

## Fayyaz, a 12- year- old with Dystrophy

“I feel jealous of the birds that fly freely everywhere. I wish I was able to move on my own without the wheelchair, if only I had the freedom...”

Muscular dystrophy (MD) is a group of muscle diseases that results in increasing weakening and breakdown of skeletal muscles over time. Many people will eventually become unable to walk. Iranian children who suffer from dystrophy are facing lack of access to medical equipment and medicine due to sanctions.



## Maryam, a 3-year-old with EB Disease

“I like my hands and my face to be beautiful.”

Maryam, is struggling with medicine shortages. Lack of access to medical supplies has caused irreversible damage to her and other EB patients. According to EB NGO officials, so far, 15 of these patients have died due to lack of medicine.





## Ali, a 6-year-old with Autism

“I like to have lots of friends, but my friends say that I scream so much and don’t play with me. Mom says that I have to take medicine to get well, but we need a lot of money to buy medicine.”

Risperidone and aripiprazole are among the medicines needed for children with autism to control the behavioral problems. The medication reduces the symptoms including the children’s sleep problems, making them more stable. Sanctions have greatly affected the access to the medicine through negative effect on both availability and affordability of them.



## Soda, a 2-year-old with Heart Disease

“I want to get back home, but they say that I have to be here. It has taken so long.”

The 2-year-old needs heart surgery but according to the doctors, due to sanctions, the equipment required for surgery are hardly available and too costly for her family.

Additionally, for those who need a Heart Valve Replacement, the Surgery costs about 10 times minimum monthly salary in a public hospital<sup>1</sup>, which is very difficult to pay for many families. The drastic increase in costs of medical care has taken place in the past two years, following serious import decrease and reluctance of foreign companies about sending medical equipment and medicine to Iran because of sanctions.

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1 . An average cost of aortic valve replacement in Iran is \$7,850.  
<https://www.medipars.com/cardiology/aortic-valve-replacement/>



## A 10-year-old with thalassemia

“I want to be healthy and don’t like the painful blood injection. I like to go to school in good health without being worried about feeling bad or dying like some of my friends who were not able to buy medicine. I feel sad for my parents who are always worried about me, my medicines and my health.”

Desferal is the name of the iron chelator that every thalassemia patient needs to get in order to treat iron overload in their blood. Some people have to use it 3 days a week and others daily. Due to sanctions, desferal is difficult to find. The domestic forms of the medicine are available but, some patients are allergic to them. If the patients do not take the medicine, iron will damage their kidneys, liver, and other organs. “Last year, about 90 thalassemia patients, and this year 60 young patients died due to unavailability of medicines.” Managing Director of Iranian Thalassemia Society, Younes Arab Said.



## Reza, a 9-year-old with Disability

“I was born with disabilities in the right hand, and both legs, but I managed to get two records in the 50-meter crawl after 4 months of professional training. I use foot prosthesis for everyday life, which has become scarce and more expensive in recent years.”

Equipment such as foot, hip and knee prosthesis has become difficult to access following the sanctions, because the prostheses are foreign products and the restrictions on financial transactions have limited access to them and increased their price.





## A 5-year- old with Hemophilia

“Whenever there is a cut in my skin, it keeps bleeding and bleeding. My wounds get long to heal. In the past, mom would give me medicine that would help a lot. Now, she says that there is very little medicine.”

Lack of access to medicine makes hemophilia patients disabled, which means that they will have to cope with the challenges of blood clot issue, multiplied with disability.



## A 6-year-old with Kidney problem

“My parents wish I was able to continue the painful medication but the machine has broken down. I am happy about that. No idea why may parents are so upset.”

Children suffering from kidney problem need dialysis treatment that filters and purifies the blood using a machine. It is necessary for people whose kidneys can't do their job. However, due to sanctions, broken dialysis machines cannot be repaired. In addition, the sanctions have increased the cost of medication for kidney disease by 100 percent making it less accessible to many patients.<sup>1</sup>

1 . <http://imed.ir/Default.aspx?PageName=News&ID=4385>



## A 5-year- old with MS

“I don’t like the painful injection. I want to be able to walk and play with my friends, to run in parks and play grounds.”

Children with MS are facing serious limitation of access to medicine due to the recent escalation of prices and the limitation of medicine import due to sanctions. Since two years ago, access to Avonex which is a disease modifying medicine has been painfully limited for all MS patients including the children.



## **Ali, a 4-year-old with cancer**

“My mom says cancer is my new friend and I have to give her medicine. But sometimes I feel really bad because I don,t have the medicine to give her.”

According to the Managing Director of MAHAK Charity-Care organization for cancer children: “Unfortunately for cancer, the bulk medicine that our children use are part of the 5% of imported medicine that are scarce and very expensive. I can say that what they claim not to have been targeted, has in fact been targeted and its impact on the lives of children with cancer is evident,” he said in a statement criticizing people who say sanctions have not targeted health and humanitarian issues in Iran.











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