### ZENDEGI MAGAZINE



### Iranian Hemophilia Society



#### Iranian Hemophilia Society Board Of Directors











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#### Dr. Fereydoun Ala

Founder of first Iranian Hemophilia Comprehensive Care Centre Founder of the Iranian Blood Transfusion Organization



#### **Mission statement**

Iranian Hemophilia society is a non-governmental, non-profit, non-political and charitable organization, which is the member of the world federation of hemophilia. Established in 1967, its main aim is to improve the quality of life for patients suffering from hemophilia and other inherited coagulation disorders through pharmaceutical, medical, social, educational and legal support as well as research and development.

We believe that by relying on philanthropic sentiments of the public and help of public and private sectors, these patients can fulfill their social role like the rest of the society. In this process we trust in paying attention to the patients' respect and organizational transparency, active participation of patients, and courage in defending members' rights.





Members of the WFH medical committee in front of the world's first hemophilia memorial statue

Special issue for the Hemophilia World Congress 2014

### Iranian Hemophilia Society

Persuading the government to provide 1.6 to 2.2 units of factor concentrates per capita for patients with hemophilia





Establishing and facilitating the first Iranian comprehensive hemophilia treatment center



Establishement of a successful prenatal prevention program through genetic assessment and genotype determination of over 2700 hemophilia families



Developing and updating the first comprehensive web-based database of Iranian hemophilia patients

### Vision 2021

Iranian Hemophilia Society is a powerful, democratic, organization with nation-wide activity playing an influential role in national and international levels. IHS has achieved its goals in line with the millennium development plans, through creating a close collaboration with the government, improving treatment and welfare of patients, establishing a sustained financial resource, engaging volunteers, and forming specialty committees within its structure. Our patient-based organization participates in continuous monitoring of the production and distribution factor concentrates within the country and the standard of care has switched to primary prophylaxis. The IHS treatment center has become a distinguished center in all fields related to hemophilia care including career recognition, women with bleeding disorders, and prenatal prevention. Three provincial treatment centers related to the IHS are active throughout the country. Most patients and their families are educated about their disease and enjoy the legal support of IHS and its cooperative companies for housing and employment. The portal database created by the IHS is the source of information for national planning, research, and management decisions concerning hemophilia care.

# Treatment for All

## Iranian Hemophilia Society



Medical and social support of Afghan and Iraqi refugees suffering from hemophilia



Presenting educational plan and providing counseling services for patients and their families.



The first hemophilia organ donation in Iran

Taha 4-year-old with hemophilia A Whose organs gave life to 7 people





Developing and establishing 28 representative offices throughout Iran.



VIIth CONGRESS
OF THE
WORLD FEDERATION OF HEMOPHILIA
TEHRAN - MAY 17 - 20, 1971



VIIth Congress of the WFH - Tehran-Iran-1971

Jamal Mohaseb founding president and CEO of the

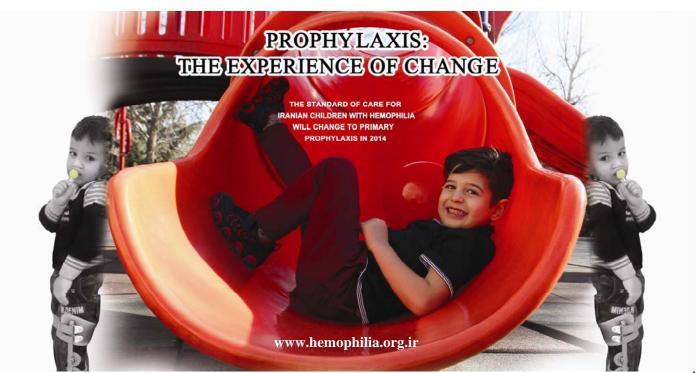
Iranian hemophilia society



Gaining distinguished international recognition
Aliakbar Tchupan (far right) Member of the WFH
executive committee 2004-2008



Presenting scientific and educational programs in collaboration with the WFH for specialists working with hemophilia







Organizing charitable activities with the help of IHS volunteers program





Hemophilia Day 2014 - TEHRAN-IRAN

Sponsored by:



Recombinant Coagulation
Factor VIIa

#### **Grandfathers with hemophilia**

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