Rare disease Foundation Of IRAN
(RADOIR)
Established in 2008
RADOIR is a non-governmental organization with national and international sphere of operation. This foundation was established in 2008 with all the assistance extended by Dr Ali Davoudian given the requirements of the health system and lack of an organization to support rare patients in Iran. Since then lots of studies done on rare diseases and in a very short period many rare diseases were identified accordingly. In Iran until now 58 rare diseases have been identified; diseases that have affected more than 1.2 million people of Iran.
Vision and Mission
Our organization vision and mission

Goals and Objectives
Our goals

RADOIR's Memberships
International Memberships

RADOIR's Achievements 2008–2019
Partnerships, Sabna, Strategic Plan, Scientific, Social, International affairs
Vision and Mission

Mission
• To provide the comprehensive clinical care for children and adults with rare diseases and disorders
• To ensure every patient across Iran, Asia & the world with equal access to the qualified expertise and care
• To establish sustainable alliances with the international centers
• To improve diagnosis, prevention and treatment for patients with rare diseases

Vision
• Rare patients living with any type of rare diseases should have full potential, regardless of nationality or residence.
Our goals and objectives:

1. Promoting rare diseases as a priority through raising **public awareness**
2. Enable children & patients living with rare diseases to receive an **accurate diagnosis**, care, and available therapy as well as medical attention
3. Developing **scientific researches** on early diagnosis and prevention as a priority
4. Inclusion **social, judicial and economic assistance** in favor of rare patients and their families
5. Raise the **profile of people** living with rare diseases
6. Developing the **methodologies** to assess the impact of diagnoses and therapies on rare patients
7. To strengthen rare disease **patient groups capacity** to act at level and to interact with other rare disease groups, internationally.
RADOIR’s Memberships

- United Nations Economical & Social Council (ECOSOC)
- Rare Diseases Europe (EURORDIS)
- Rare Diseases International (RDI)
- International Conferences on Rare Diseases (ICORD)
- International Coalition of Organizations Supporting Endocrine Patients (ICOSEP)
- Cancer Epigenetics Society (CES)
- International Society of Neonatal Screening (ISNS)
- Asia Pacific Alliance of Rare Diseases Organizations (APARDO)
RADOIR’s Achievements 2008–2020 (Partnerships)

Countersigned Partnership MOU’s with:

- EURORDIS & Rare Connect
- Tehran University of Medical Sciences (TUMS)
- Iran University of Medical Sciences (IUMS)
- Shahid Beheshti University of Medical Sciences (SBUM)
- Ministry of Labor & Social Welfare of Iran
- Ministry of Education of Iran
- National Brain Mapping Laboratory (NBML)
**SABNA**

is RADOIR’s rare patient’s registry system and the target societies are:

- The Patients
- Head of laboratories
- Service officers
- Physicians
- Moderators of the Associations
- Receptionists

**Scope**

The system is applicable for hospital, laboratory, clinic or medical centers to receive and save patients’ information for future treatments.

**Modules of the systems**

- Moderating users
- Reports
- Patients’ documents
- Pharmaceutical data bank
- Laboratory and Medical Images
- Medical services
The Iranian National Strategic Plan For Rare Diseases

RADOIR is developing the Iranian strategic plan for Rare Diseases in collaboration with Tehran University of Medical Sciences (TUMS). The main goal is Better lives for people with rare diseases and their families and the significant targets are as:

- Diagnosis
- Medical treatment
- Education and empowerment
- Patient networks
- Support and assistance
- Legislation
RADOIR’s Achievements 2008–2020 (Scientific)

01. **RADOIR’s ATLAS of RARE Congenital & Genetic Disease (2018-2019)**
02. Scientific oral & poster presentations on rare diseases and orphan drugs at local & int’l events
03. Holding the first Iranian Rare Patients Medical Committee at RADOIR
04. Organizing nine local & international conferences on the occasion of Rare Disease Day
05. Rare Diseases Awareness workshops in collaboration with the Ministry of Education Health Experts of Iran - Dec. 2018
06. Publication of 41 national scientific journal editions and books on rare diseases
07. Replacing of Molecular therapy with chemical therapy for rare cancers patients
08. Scientific research and surveys of the health screening programs to identify rare patients
09. Annual Free patients’ Medical Visits By RADOIR’s Medical Team (2015-2018)
10. To be continued...
Children with Rare Diseases at the First Joy Campaign of RADOIR
RADOIR’s Achievements 2008-2020 (Social)

Food & Handcrafts
RADOIR at Food & Handcrafts In Collaboration with Diplomatic Women Assembly

Happy campaign
Holding happy campaign for rare children together with their families

Free Patients’ Medical
Annual Free patients’ Medical Visits By RADOIR’s Medical Team

Free Family Consulting
Organizing free family consulting sessions for the rare patients

Meeting sessions
Periodical meeting sessions with rare patient associations

Health events
Joining various local & international health events to share experiences and raise the public awareness on rare diseases
RADOIR’s Achievements 2008–2019 (International Affairs)

Oral presentations at international conferences on rare diseases and orphan drugs like:

- Asian Rare Diseases Conference in Malaysia – Nov. 2016
- Orphan Drugs Congress in Brussels – Nov. 2016
- CoNGO session at UN headquarters in New York – Nov. 2016
- 20th EURORDIS Annual Session in Budapest – May 2017
- 3rd RDI Annual Session in Barcelona – June 2017
- 12th Int’l Conferences on Rare Diseases & Orphan Drugs (ICORD) in Pekan – Sep. 2017
- 9th European Conference on Rare Diseases (ECRD) in Vienna – May 2018
- 13th Int’l Conferences on Rare Diseases & Orphan Drugs (ICORD) in Stockholm – Sep. 2018
- 27th EURORDIS Roundtable of Companies Workshops (ERTC) in Barcelona – Oct. 2018
- 1st EURORDIS Steering Committee Session with RADOIR in Paris – Nov. 2018
- 1st Epigenetics & Epitranscriptomic Int’l Conference in Helsinki – Nov. 2018

Official visit to pharmaceutical companies in Europe (Spain, Netherlands, Belgium, …)
RADOIR’s Achievements 2008-2020 (Social)

- 335 types of Rare Diseases in Iran
- 4,000 Rare Patients
- 3,105 Rare Patients registered at SABNA

www.radoir.org/sabna

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THANKS!

Do you have any questions?
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