



Rare disease Foundation Of IRAN

(RADOIR)
Established in 2008





HISTORY

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

01

02


03

04

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
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Vision

- Rare patients living with any type of rare diseases should have full potential, regardless of nationality or residence.
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Goals & Objectives

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 Nation
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

GES



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)

RADOIR's Achievements 2008–2020 (SABNA)

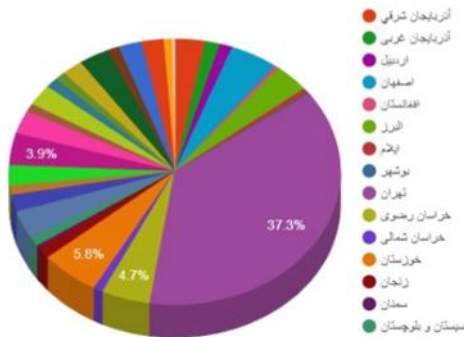
SABNA

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:

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- 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



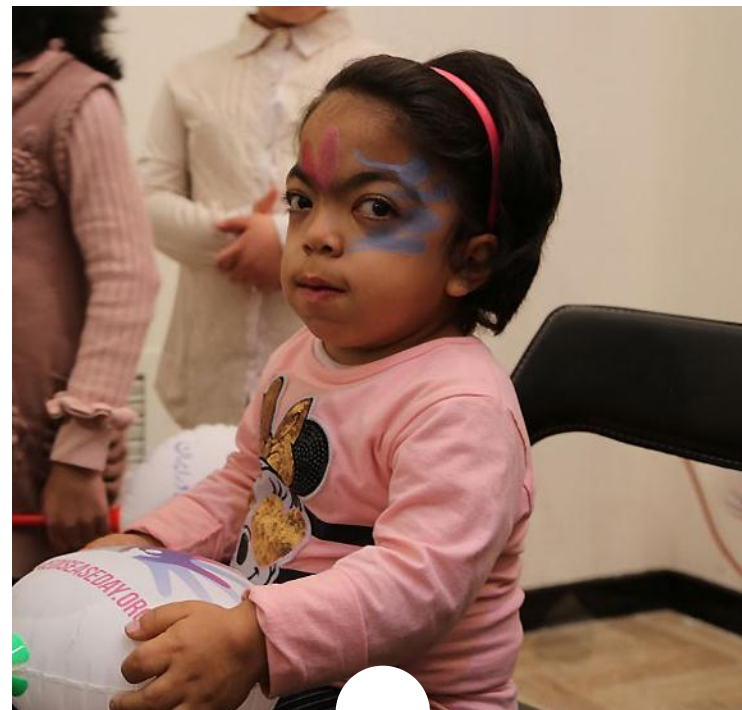
4,000

Rare Patients



3,105

Rare Patients registered at SABNA



www.radoir.org/sabna

last updated date: 2020/06/21

THANKS!

Do you have any questions?

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<http://instagram.com/rarediseaseir>

