

Foreword

It is noteworthy to mention that the idea to establish a non-governmental organization (NGO) occurred to Dr.Ali Davoudian in 2005. The mystery of rare diseases and patients in Iran, just like a flicker to a flame made him to begin a vast research survey to discover further problems with rare patients and focus on providing the required medical and therapeutic services for them as the first rare patients organization registered on 7th March 2009 in Iran.RADOIR's outstanding achievements resulted from the innovative ideas and humanitarian purposes significantly motivated the local and international healthcare specialists to start their global awareness raising collaborations with Rare Diseases Foundation of Iran.

Due to the lack of sufficient information on the rare disease patients in Iran, it was necessary to prepare RADOIR agenda dependently, since no regulated activity neither in private nor in governmental sector, performed in favor of the rare diseases and rare patients to draw a global-based definition, accordingly and to identify the counterparts in other countries in mutual interaction with each other to establish database and make the use of the viewpoints of the sub-specialists in favor of RADOIR's mission and vision.

About Us

Rare Diseases Foundation of Iran (RADOIR) is a non-profit and independant with national and international sphere of operation. This foundation was established in 2009 with all the motivation and assistance extended by Dr.Ali Davoudian to promote the health system and lack of an organization to support rare disease patients all over Iran.

Rare Diseases Foundation of Iran is a NGO as member state of EURORDIS, RDI, ICORD, RareConnect and with ECOSOC Special Consultative Status ,... 100% independent and private sector in Iran which was established in 2008 and believes in the theme: "Rare Disease Patients Without Borders".

RADOIR is the only NGO in charge of rare diseases which has been invited to the establishment of Rare Diseases NGO Committee.About 150,000 rare patients are supported with free of charges services 24 hours a day by RADOIR medical center.

In Iran until now, 58% of the rare diseases have been identified which have affected more than 1.2 million of its population.We are the only data reference for supporting the rare patients all over Iran. There are patients societies in partnership with RADOIR as : ALS, MPS, EB, CP, RP, NBIA, PKU, Lupus, Distrophy, etc.



These are the most delightful days of my life. The bright days of success and healthcare promotion in globalizing Rare Diseases Foundation of IRAN and presenting our goals and approaches to the Asian, European and United Nations Counterparts. We seriously aim to expedite the clinical development of orphan drugs and facilitate access to treatment for rare disease patients and their families in collaboration with our partners. Also be the qualified experts in the regulatory and clinical development of orphan drugs, interacting with companies, patient groups, key opinion leaders, funders in all over the world. We are to prove that our actions to serve the rare patients, share academic and innovative ideas and to devote our humanitarian emotions, speak louder than words beyond the boundaries. Rare Patients without Borders! “



Dr. Ali Davoudian
RADOIR Founder



Dr. Hamid Reza Edraki
Managing Director

In the last decade, the status of early diagnosis has become more valuable than before. Early detection of rare disease is more important than the treatment and better prognosis. Genetic study and medical imaging work up are compatible for managing rare diseases. I think, early diagnosis by fetal imaging such as MRI, early genotyping screening by amniocentesis will help us to discover how a rare disease proceeds. Hope for prompt detection of rare diseases in the world. Life is beautiful, but time is so tight, let's help each other for better life in this short time. Believe and trust together for all.

Rare people have rare lives with significant differences. Talking about somebody's values, we use metaphors to affiliate it to the nature, like sun in generosity, mountain in persistence, sea in greatness, but some people are themselves the symbol of rareness, rare like RD patients, rare like Dr. Ali Davoudian, the father of Rare Diseases in Iran. The responsibility of caring rare patients turns out to be RADOIR's greatest mission in his absence; through dedicating developing skills and making progress, RADOIR's authorities and RD patients will achieve their goals and objectives. Now I am at my father's feet and wish to help his dreams to come true, this is like a burden on my shoulders. We, RADOIR, are here to do our best in order to ease patients' life and relieve their pain, hopefully.



Yaser Davoudian
Chairman

Goals & Objectives



Goals & Objectives

With the purpose of improving and supporting the lifestyle quality of the rare patients and development of the rare diseases medical services, Rare Diseases Foundation of Iran is pursuing following goals and objectives:

- Carrying out research and field studies on rare diseases and their impacts upon the affected individuals
- Raising awareness on the rare diseases and extending financial and collaborative support (donation and endowment) in favor of rare patients, the disabled and the handicapped suffering from rare diseases.
- Identifying patients suffering from different types of rare diseases, preventing further prevalence, supporting and empowering the affiliated patients
- Building up and developing RADOIR's representative offices and branches as well as further empowerments through financial and structural assistance and collaboration
- Publication of rare diseases specialized references, reports, books and scientific journals
- Holding workshops, seminars, forums and scientific conferences on rare diseases and the methods for rehabilitation of the affected individuals
- Extending and carrying out social, judicial and economic assistance in favor of rare disease patients and their families
- Establishment of supportive centers for prevention, counseling services and developing rare patients unity, empowerment, educational and academic institutions
- To strengthen the voice of the patients suffering from the rare diseases, globally
- To showcase the rare diseases as a global challenge
- To promote the status of the rare diseases as the priority of the international public healthcare
- To organize, promote the achievements and support the partnership investment policies and projects on the rare diseases all around the world, accordingly
- To facilitate the early diagnosis of the rare diseases and to achieve the best medical and healthcare standards
- To achieve the access to the effective orphan drugs and treatment methods
- To improve the living condition and quality of rare patients to discover further treatment solutions for the rare diseases
- To access the qualitative information and awareness raising of the rare patients



Collaborations

- RADOIR & Ministry of Education Collaborations on Rare Diseases Training Courses for School Principals of Iran
- Establishment of the 1st Iranian Rare Patients Medical Committee at RADOIR
- Diagnosis and pharmaceutical local & international cooperation for the rare patients' benefits
- Joining IRAN PHARMA International Pharmaceutical Trade Fair
- RADOIR at the world community of Rare Disease Patients
- Rare Patients ID's at RADOIR's Psychological Consulting Center
- Sweden's inclination for investing on the Iranian Rare Patients
- Ministry of Foreign Affairs & Ministry of Labor & Public Affairs in collaboration with RADOIR
- Medical Specialties Clinic for Rare Diseases at RADOIR
- Annual Rare Diseases patients meeting sessions with official authorities in Iran
- RADOIR and National Brain Mapping Laboratory Collaboration (NBML)
- RADOIR Membership at European Medicine Agency (EMA)
- RADOIR Affiliate Membership at RareConnect, EUROCAT & ORPHANET



Diagnostic & Therapeutic Services

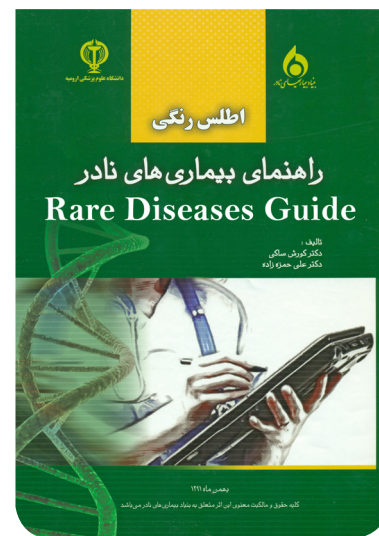


- Establishment of Rare Specialties Clinic for rendering free of charge supportive and medical services: internal medicine, Infectious Diseases, Cardiac, Neurosurgery, Obstetrics and Gynecology, Orthopedics, General Surgery, Genetics, Psychology and Pathobiological and Medical Diagnosis Laboratory
- Establishing RADOIR's Psychological and Consulting
- Organizing the Permanent Medical Committee for diagnosis of rare diseases
- Rendering free of charge medical therapeutic and diagnostic services to the rare patients through RADOIR's medical centers and all other ones in contract agreement status with RADOIR
- Rare patients referral to other medical centers in the country
- Genetic samples of the rare patients referral to the genetic centers abroad
- Extending invitation to the medical experts and researchers residing abroad in order to have a visit and examine rare patients in Iran twice a month at the venue of RADOIR clinic

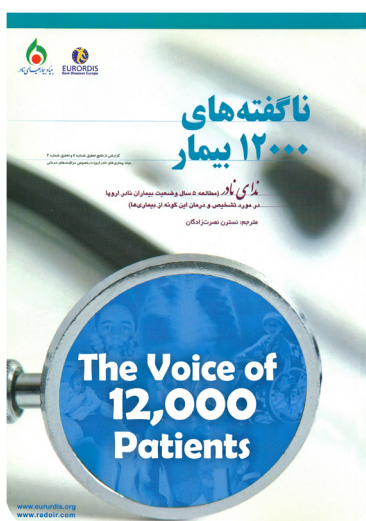
Scientific Research & Activities

RADOIR has always been trying to establish and maintain non-stop collaboration with the counterpart academic, R&D centers engaged with the rare case studies and reports:

- Preparation of the Atlas for Rare Diseases in cooperation with the West Azerbaijan University of Medical Sciences
- Translation and publication of the book “Voice of 12,000 patients with Rare Diseases” in 50,000 copies in cooperation with the ECO Cultural Institution in the Persian ECO region
- Holding the scientific congress on Muscle Atrophy and Myasthenia and rare psychological syndromes and immune deficiency disorders
- Organizing the scientific congress; bio-information, early diagnosis of the rare disease and treatments, medical genetics, replacement of molecular therapy with chemical therapies for the patients affected by cancer
- Holding the scientific congress on identification of solutions and remedies for prevention and rare diseases prevalence
- Organizing the scientific symposium on Metabolic and genetic rare diseases
- Scientific surveys of the health screening programs done to identify rare patients and the relevant causes.



- Oral & poster presentation, abstracts and case reports on rare diseases at international congresses and conference worldwide
- Awareness raising through social & public media
- Organization of nine local and international conferences and seminars on the occasion of international Rare Disease Day
- Issuance of Rare Health ID Card for rare patients in Iran with the support of Rare Diseases Foundation of Iran
- Publication of 41 journal editions and books on rare diseases
- Providing all rare patients with Health & Medical Treatment Insurance Services card
- Holding periodical meeting sessions with the presidents of rare disease societies in Iran and abroad
- Medical treatment via bio-information
- Early diagnosis of the rare diseases and genetic disorders to achieve the effective treatment
- Replacement of Molecular therapy with chemical therapy for the patients suffering from cancer



Circadian Rhythm, Lifestyle and Health

Prof. Dariush FARHUD



The circadian rhythm as an internal self-sustained oscillator in cells, plays a crucial role in people's healthy lives which is affected by factors consisting of cosmic events related to the universe and earth, environmental factors (light, night and day duration, seasons) and lifestyles. In humans, dysfunction or misalignment of the circadian clock with environmental cues alters the timing of the sleep-wake cycle, leading to a variety of circadian rhythm sleep disorders. It has been appreciated that the central role of circadian rhythms play in coordinating organism's life with earth's day.

Prof. Dariush D. Farhud has completed his PhD at the age of 34 years from University of Mainz, Germany, and professorship in Medical Genetics, University of Munich, Germany.

He is Founder and Head of the first Department of Human Genetics and Anthropology in Iran, Tehran University of Medical Sciences, the head of Genetic Clinic of Dr. Farhud, Tahrán, Iran.

Future Hereditary of Rare Diseases & Orphan Drugs

Dr. Mohsen Sojoudi



Bioinformatics resources and database tools about the genetic disorders, useful management of sample sequences and post-transcriptional regulation could be the starting point for solving the difficulties on the identification of rare diseases.

Making a right and timely diagnosis is coming to be a significant difficulty for rare diseases delayed diagnosis.

He was graduated from Ferdowsi University (Meshhad - Iran) in Information Technology. At the time being, he is Senior IT consultant and manager at Rare Diseases Foundation of Iran and Parsian Medical Center. Dr. Sojoudi has achieved healthcare and IT systems promotions through his self-motivated researches on the rare diseases data analysis

Fetal MRI in Early Diagnosis of Brain

Dr. Hamid R. EDRAKI



Magnetic Resonance Imaging (MRI) value through the abnormalities which are not well evaluated with sonography and screening in general, is the initial means for fetal (CNS) malformations. Through various MRI practicing reports, CNS or central nervous system is quite common fetal MRI indication.

All examinations are on a 1.5 tesla magnet performance utilizing a torso coil in most circumstances.

Dr. Hamid Reza Edraki was graduated in Neuro-radiology (MRI) from LMU University (Munich-Germany). At the time being, he is associate professor at Shahid Beheshti Medical University in Iran and Managing Director at Rare Diseases Foundation of Iran and the Chief Radiologist at RADOIR's Parsian Medical Center. Dr. Edraki has achieved many outstanding academic screening researches on rare diseases and its types in their broad aspects.

Evaluation of INOS, ICAM-1& VCAM-1 Gene Expression

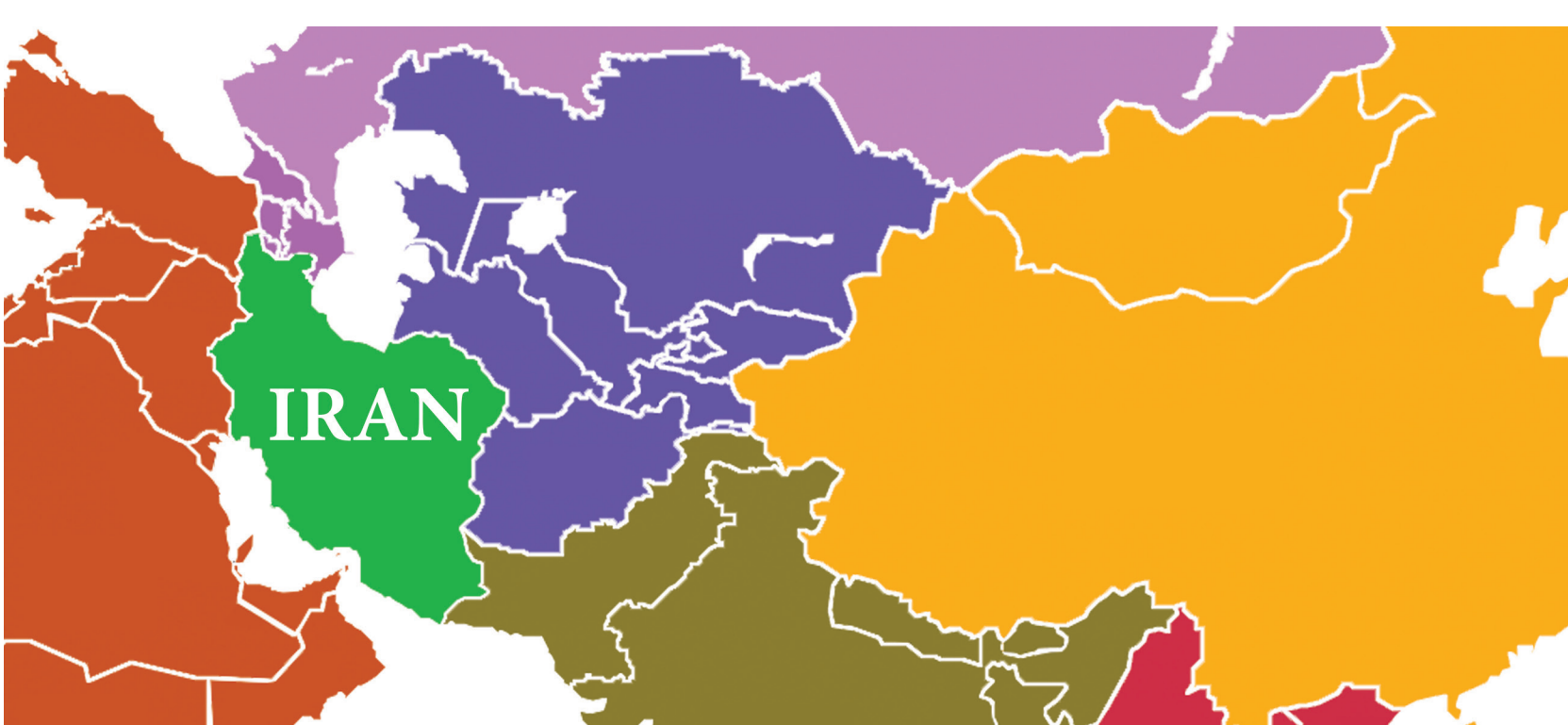
Dr. Mehdi Norouzi



The main aim of this study was to evaluate the expression of intercellular adhesion molecule-1 (ICAM-1), vascular cell adhesion molecule-1 (VCAM-1), and inducible nitric oxide synthase (iNOS) as host factors, and proviral load as the viral parameter, in adult T-cell leukemia/lymphoma (ATLL) individuals and healthy carrier (HC(s)) groups.

Dr. Mehdi Norouzi has completed his PhD in Molecular Genetics from National Institute of Genetic Engineering and Biotechnology and Virology from Tarbiat Modarres University.

He is a member of the Department of Pathobiology, Division of Virology in Tehran University of Medical Sciences and Rare Diseases Foundation of Iran.



Rare Patients Without Borders



RADOIR Medical Clinic

Clinical Medicine Services

- General & Pediatric Surgery
- Orthopedic
- Pediatrics & Infants
- Heart Diseases
- Glands
- Infectious Diseases
- Nutritional Counseling
- Electromyography

www.pmic.ir

Imaging Services

- MRI (1.5 Tesla)
- Sonography(color Doppler)
- Spiral CT-Scan
- Digital Radiology
- Digital Panoramic Periapical
- Mammography (Digital)
- Bone Mineral Densitometry
- Gynecology, Obstetrics

www.radoir.org/fa/clinic

Laboratory Services

- Microbiology
- Hematology
- Biochemistry
- Hormone
- Viral
- Serology
- Neurosurgery
- Neurology
- Psychiatry
- Ophthalmology
- Physical Medicine
- Electrocardiogram
- Injections
- Wound Care
- Plastering
- OR Surgery

www.radoir.org/fa/azmayeshgah

Rare Disease Societies in Iran



- RP Society
- Lupus (DLE) & (SLE) Society
- Alopecia Society
- Muscular Dystrophy (MD) Society
- Immune Deficiency Society
- EB Society
- CP& Mental Disorder Society
- Ichthyosis Society
- MPS(Mucopolysaccharidosis) Society
- NBIA (Hallervorden) Society
- Cystinosis Society
- Rare Diabetics Society
- ALS Society
- NF (Neurofibromatosis) Society
- Gaucher's disease Society
- MG (Myasthenia Gravis) Society
- Rare Cancer Society
- Metabolic Society
- Coeliac Society
- Leprosy Society
- Phenylketonuria (PKU) Society