10TH INTERNATIONAL CONGRESS ON THE OCCASION OF RARE DISEASE DAY

March 2nd , 2019 Tehran-Iran

RARE but not ALONE!

The **10th international congress on the occasion of Rare Disease Day** will be held on Feb. 28, 2019 in Tehran by Rare Diseases Foundation of Iran (RADOIR).
RADOIR is a NGO as member state of ECOSOC, EURORDIS, RDI, ICORD, ICOSEP (ISE), CFRD (Committee for Rare Diseases), Rare Connect, CES... and 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 supporting the patients all over in Iran.

RADOIR Achievements 2018-2019:

- Establishing SABNA (Strategic Analysis Bio-genetic National Assessment) patient registry system
- Signing scientific MOU with Tehran University of Medical Sciences (TUMS), Iran University of Medical Sciences (IUMS), National Brain Mapping Laboratory (NBML) and the Iranian Ministry of Education
- Endorsed by TUMS for launching the Farsi version of ORPHANET
- Countersigned MOU with EURORDIS on partnership
- Countersigned MOU with RareConnect on launching the Farsi version of the network
- Holding periodical sessions with RD societies in Iran
- Having confirmation of FDA as well as MOH in Iran to have a Rare Patients Pharmacy
- Approved by the Iranian Ministry of Health to codify National Rare Diseases Strategic Plan
- Holding training workshops for primary schools instructors and educators

2019 RADOIR congress will be held in 2 panels: Scientific and Social:

Panel 1 – Scientific Approaches

Objectives:

- Screening , Pre-Pregnancy and Peri-natal Consultations
- Clinical & Laboratory Diagnostic Interventions of Rare Disease
- Medical Ethnics for Rare & Genetics Diseases
- Palliative & Supportive Interventions : Pharma & Non-pharma Therapeutics for Rare Diseases

Panel 2 - Social Approaches

Objectives

- To honor Rare Disease Day and support the Iranian rare patients, children and their families as well as those of all over the world.
- To make every one hear the voices of rare patients about their met and unmet needs as pharmaceuticals and their therapeutic and healthcare system

RADOIR International Dept.:

Telefax: +98 (21) 66572937 & 66572947
Email: international@radoir.org