

لیست ارسال ها

## National Program for Disease Registry

### Report form of Registration Program

**Developing start date:**

04/20/2013



**Name of Registry:**

Iranian Cystic Fibrosis Registry (ICFR)

**Type of outcome:**

Other health outcomes



**Type of Registry:**

Clinical(Quality of care)



**Scope:**

National (Multi center)



**Definition of the Outcome:**

The Iranian Cystic Fibrosis Registry (ICFR) is a centralized database of CF patients in North-western of Iran that collects information on the demographic, clinical data, laboratory results and Follow upping patients. Information is collected on hospitalizations and outpatients CF patients in the Educational and Treatment Children?s Hospital from 2001 to 2018 with a goal to support research, education and presentation services on CF and develop cooperation with other provinces in Iran.

**Objectives of the Registry:**

Registries are considered essential tools designed to measure all health-related aspects of cystic fibrosis (CF) and to compare clinical data from different centers and countries. All the information in the ICFR is held confidentially with Linking and disturbing capability for other medical members in Iran. ICFR Report may show an important tool to analyze demogherafic, clinical and paraclinical characteristics of the disease as well as to apply for healthcare governmental programmes based on health care data.

**List of Minimum Dataset (Variables):**

- Patient demographics
- Administrative data
- Survival data
- Diagnostic procedures
- Disease genotype and clinical manifestation
- Therapeutics

**Registry Biobank:**

No  Yes

**Biobank Sample Type**

Is proceeding

**Biobank More Description****Data Entry start date:**

04/20/2013

**Sample Size (Up to 31 June 2018):**

550

**Secretariat:**

Liver and Gastrointestinal Disease Research Centre. IMAM REZA Hospital, Tabriz, Iran. 041-33367473

**Financial Support Resources:**

Universities od Medical Sciences ▼

**Other Financial Support Resources:****Number of Collaborating Centers:**

1-4 ▼

**Collaborating Centers:**

Children`s hospital of East and West of Azerbaijan Province,  
Children`s hospital of Ardabil Province  
Medical Genetic Laboratory of Tabriz

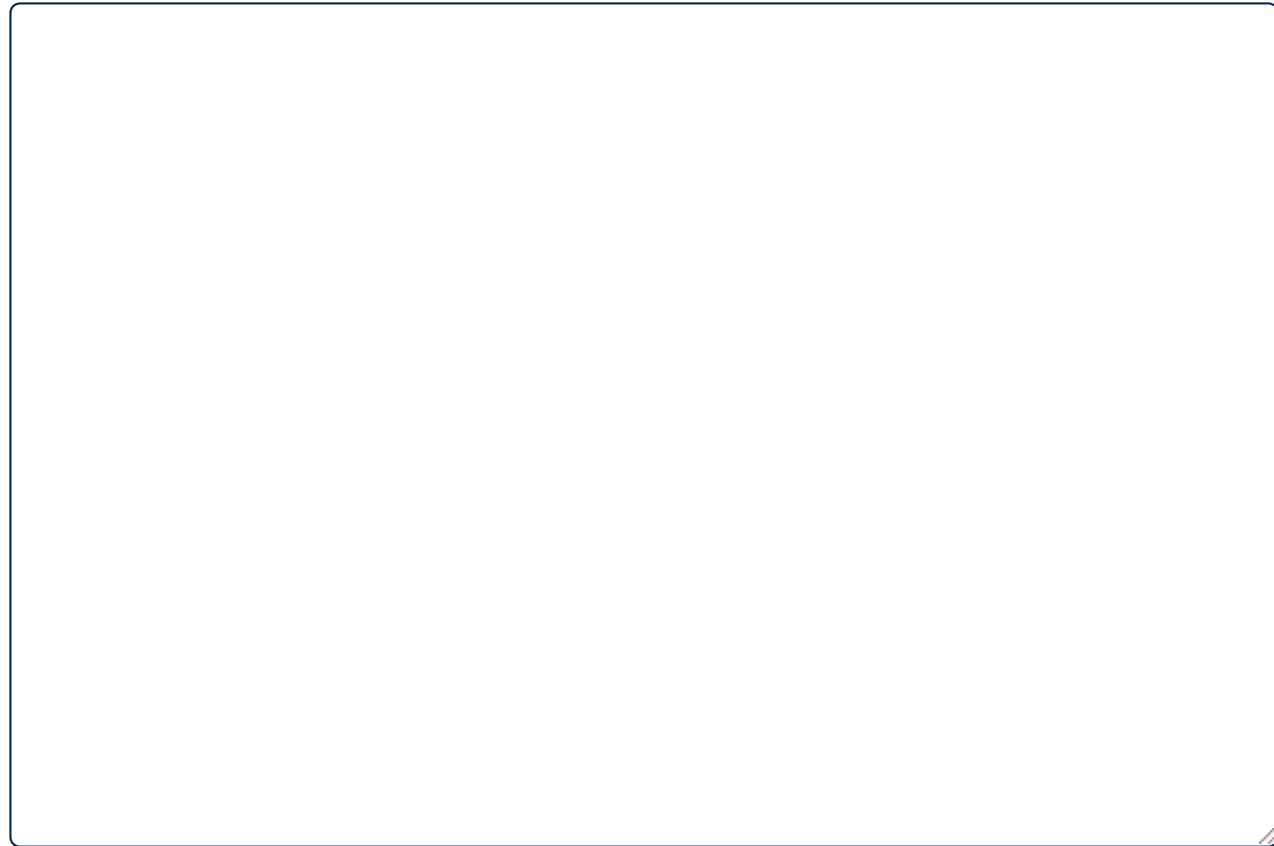
**International Collaboration:**

No  Yes

**Number of International Centers:**

1-4 ▼

**International Centers:**



**Name of Software:**

CF Information Registry System. [www.icfreg.ir](http://www.icfreg.ir)

**Software Company:**

شرکت تصمیم یاران مدیریت ایرانیان <http://health.techmart.ir/company/view/CMP-2376/%D8%B4%D8%B1%DA>



**Registry Guideline**

Is proceeding...

**Number of peer-reviewed publication  
(ISI/PUBMED):**

9

**Number of peer-reviewed publication  
(except ISI/PUBMED):**

**Number of Farsi Publication:**

4

**Complete List of Publication (Vancouver)**

- Spectrum of CFTR Gene Mutations in Iranian Azeri Turkish Patients with Cystic Fibrosis.  
Mortaza Bonyadi, Omid Omrani, Mandana Rafeey, and Nemat Bilan
- Minimum Data Set for Cystic Fibrosis Registry: a Case Study in Iran.  
Leila R Kalankesh, Saeed Dastgiri, Mandana Rafeey, Narmin Rasouli, and Leila Vahedi
- Association Between Outcomes and Demographic Factors in an Azeri Turkish Population With Cystic Fibrosis: A Cross-Sectional Study in Iran From 2001 Through 2014.  
Leila Vahedi, Morteza Jabarpoor-Bonyadi, Morteza Ghojzadeh, Hakimeh Hazrati, Mandana Rafeey
- Gender Differences in Clinical Presentations of Cystic Fibrosis Patients in Azeri Turkish Population.  
Leila Vahedi, M.D., Ph.D., Morteza Jabarpoor-Bonyadi, Ph.D., Morteza Ghojzadeh, Ph.D., Amir Vahedi, M.D., Mandana Rafeey, M.D.
- Association of TNF- $\alpha$  Gene Variants With Clinical Manifestation of Cystic Fibrosis Patients of Iranian Azeri Turkish Ethnicity.  
Aziz Khorrani,\* Mortaza Bonyadi, Mandana Rafeey, Omid Omrani
- Genetic pattern of cystic fibrosis patients in Azeri Turkish population.  
Jabarpoor-Bonyadi Morteza ,Rafeey Mandana ,Vahedi Amir ,Vahedi Leila
- Correlation Genotype-phenotype in Cystic Fibrosis According to Registry Center of Cystic Fibrosis  
Mandana Rafeey, Morteza Jabarpoor-Bonyadi, Leila Vahedi
- Recombinant human growth hormone effects on growth in cystic fibrosis  
R Ghergherechi, M Rafeey
- Sinopasal Manifestations in Children with Cystic Fibrosis

**Number of Conference Abstract:**

4

**PI (principle investigator):**

Prof.Dr. Mandana rafeey.MD , Pediatric Gastrointestinal and Liver Disease

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**Registry Manager:**

Dr Leila Vahedi

**Manager Email Address:**

Vahedi.l149@gmail.com

**Telephone Contact of Registry:**

09141146982- 09141088054

**Website:**

https://icfcu.tbzmed.ac.ir

**Attachments (Logo, Photo of PI, List of Variables, Annual Report) .zip/.rar:**

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