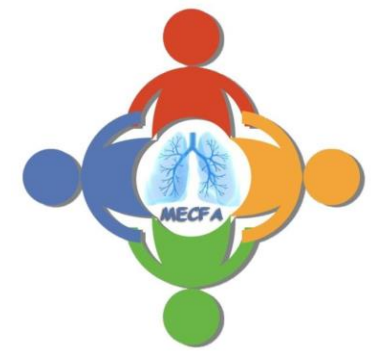




Iran CF Foundation



CF in Iran

Mohammadreza Modaresi, MD

Pediatric pulmonologist

President of Iran Cystic Fibrosis Foundation (ICFF)

3rd MECFC, Istanbul

21-23 March 2019

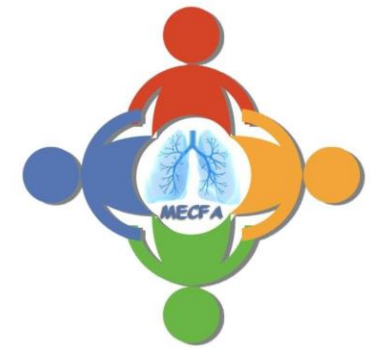
info@cfiran.com

modaresipul@gmail.com



Iran CF Foundation(ICFF)

CF in Iran

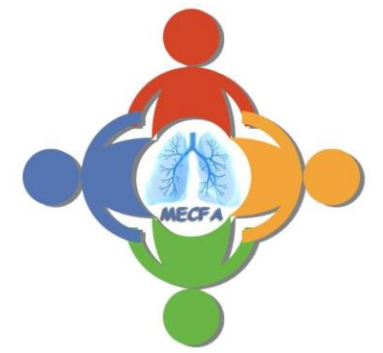


1. CF Prevalence
2. CF Center
3. CF Registry
4. CF facilities
5. CF Foundation
6. CF genotyping
7. CF Training programs
8. CF Researches
9. CF newborn screening



Iran CF Foundation(ICFF)

CF Prevalence in Iran

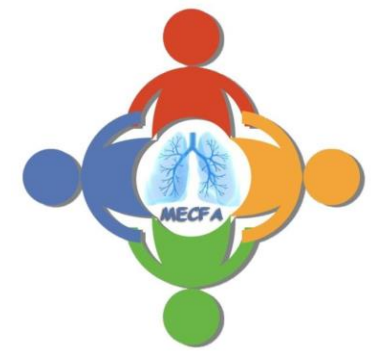


- How many cases of cystic fibrosis are there in Iran?
- There are two concepts about CF prevalence in Iran:
 - The old concept said CF is extremely rare in Iran
 - The new concept says cystic fibrosis is an almost common problem in our country



Iran CF Foundation(ICFF)

Cf prevalence in Iran



- 25 to 30 new CF cases are diagnosed monthly at children medical center (CMC) Hospital As a largest referral children hospital in Iran.



J Educ Health Promot. 2017 Jun 5;6:54. doi: 10.4103/jehp.jehp_80_15. eCollection 2017.

Cystic fibrosis prevalence among a group of high-risk children in the main referral children hospital in Iran.

Modaresi MR¹, Faghinia J², Reisi M², Keivanfar M², Navaie S¹, Seyyedi J³, Baharzade F².

+ Author information

Abstract

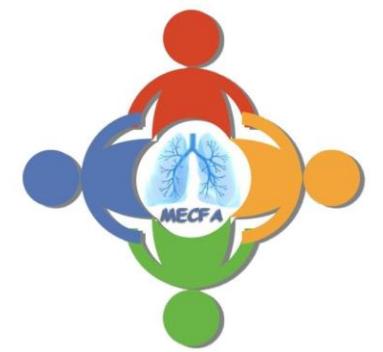
BACKGROUND: Knowledge about cystic fibrosis (CF) in Iran is very limited. The objective of this study was to determine the prevalence of CF among a group of high-risk children with suggestive clinical features in the main referral hospital in Iran.

MATERIALS AND METHODS: This study children consisted of 505 patients who had presented with one or more of the following symptoms: chronic or recurrent respiratory symptoms, gastrointestinal symptoms as rectal prolapse, steatorrhea, hepatobiliary disease as prolonged jaundice, failure to thrive, hyperglycemia and glycosuria, hypochloremic metabolic alkalosis, hypoprothrombinemia, anemia or edema, and positive family



Iran CF Foundation(ICFF)

CF prevalence in Iran

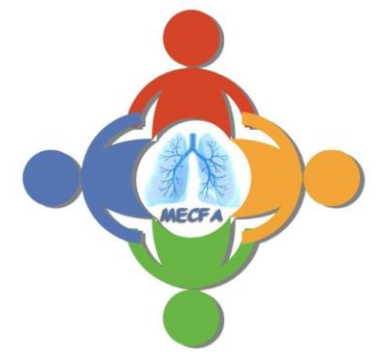


- At our reference CF center, we have recently performed an initial screening of **~27,000** potential CF patients for 5 years
- 5-7% of these children (**1650**) were diagnosed with CF based on the sweat test and further characterized
- We don't know the exact number of CF patients in Iran but we guess around 4000-5000 CF patients are living in Iran



Iran CF Foundation(ICFF)

CF Center at CMC



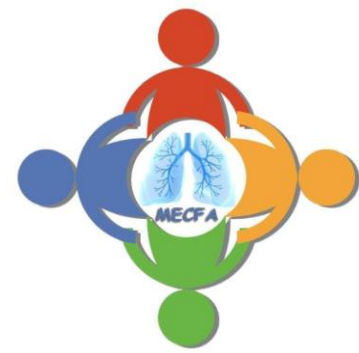
- The first cystic fibrosis center (**CF Center**) has started activities at the Children's Medical Center (CMC), in **2012.**





Iran CF Foundation(ICFF)

Multidisciplinary team at CF Center



1. Pediatric Pulmonologist
2. Pediatric Gastroenterologist
3. Pediatric Endocrinologist
4. Pediatric Psychologist and Psychiatrist
5. Respiratory Physiotherapist
6. pharmacotherapies
7. Nutritionist
8. Clinical microbiologist
9. Social worker



Pediatric Pulmonologist



Dr Modaresi



Dr Navai



Dr Shirzadi

Ped Gastroenterologist



Dr Najafi



Dr Farahmand



Dr Motamed



Dr Alimadadi

Ped endocrinologist



Dr Setoodeh

Social worker

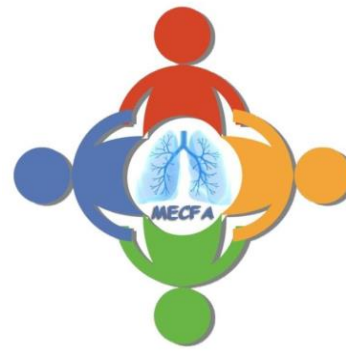


Mrs Alai

Dietitian



Mrs ghalegri



pharmacotherapies



Dr Rangraz

Respiratory Physiotherapist

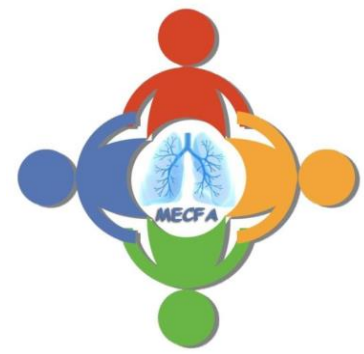


Mrs Alirezai



Iran CF Foundation(ICFF)

Our newest member



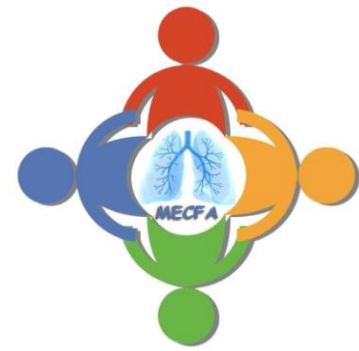
- Kazemzade MD
- He is an Adult Pulmonologist which is training in our center to cover adult patients.





Iran CF Foundation(ICFF)

CF REGISTRY



- All the CF patients are registered at the CF foundation data base registry

<http://iran-cfregistry.com/>



Iran CF Foundation(ICFF)

first page of registry web

[Home](#) . [Edit Profile](#) . [Register New User](#) . [Total Registered Users](#)

ali yaghoobi

[Sign Out](#) 

Our Patient List

First Name

Last Name

In all patients



علیزاده امیر رضا

فتحیان امیرعباس

حق نژاد مهشید



add new patient



Total Register Patient



Report



Setting



add new patient



First Name

Last Name

National Code

Sex

Life Status

Date of Birth

Age(Year)

Age(Mounth)

Date of Death

Age at Death

Date at
Diagnosis

Age at
Diagnosis

Province Of
Birth

City Of Birth

Visit Date

Save

- Encounter Data
- Respiratory Microbiology (ENCOUNTER DATA)
- Pulmonary Medications (ENCOUNTER DATA)
- GI/Nutrition/Endocrine Medications (ENCOUNTER DATA)
- Pulmonary Function Tests(ENCOUNTER DATA)
- Complications (ENCOUNTER DATA)
- Lab (ENCOUNTER DATA)
- Act/Exercise (ENCOUNTER DATA)

Data  

Patient Info



Name :

Visit Date

Save

Visit Summary



Medication

Visit Forms

BMI Calculation

Height(M)

Height (cm)

Weight (kg)

BMI value

Weight for Length percentile

Location

Height (Percentile)

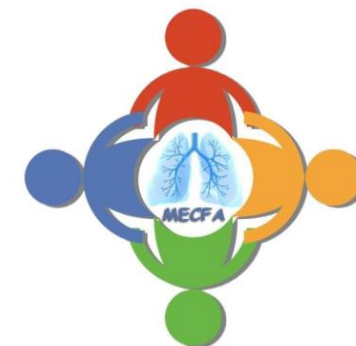
Weight (Percentile)

BMI (Percentile)

Exacerbation Assessment



Iran CF Foundation(ICFF)



Web-based registry

Home . Edit Profile . Register New User . Total Registered Users

ali yaghoobi

Sign Out

Patient Count : 888

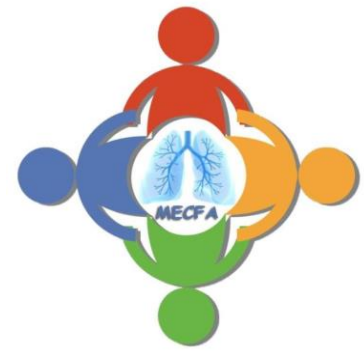
No.		Select	FirstName	LastName	Date Of Birth	Sex	City Of Birth
1	<input type="checkbox"/>		امير رضا	عليزاده	6/14/2011	Male	Tehran
2	<input type="checkbox"/>		اميرعباس	فتحيان	3/20/2016	Male	Behbahan
3	<input type="checkbox"/>		مهشيد	حق نژاد	6/3/1996	Female	Karaj





Iran CF Foundation(ICFF)

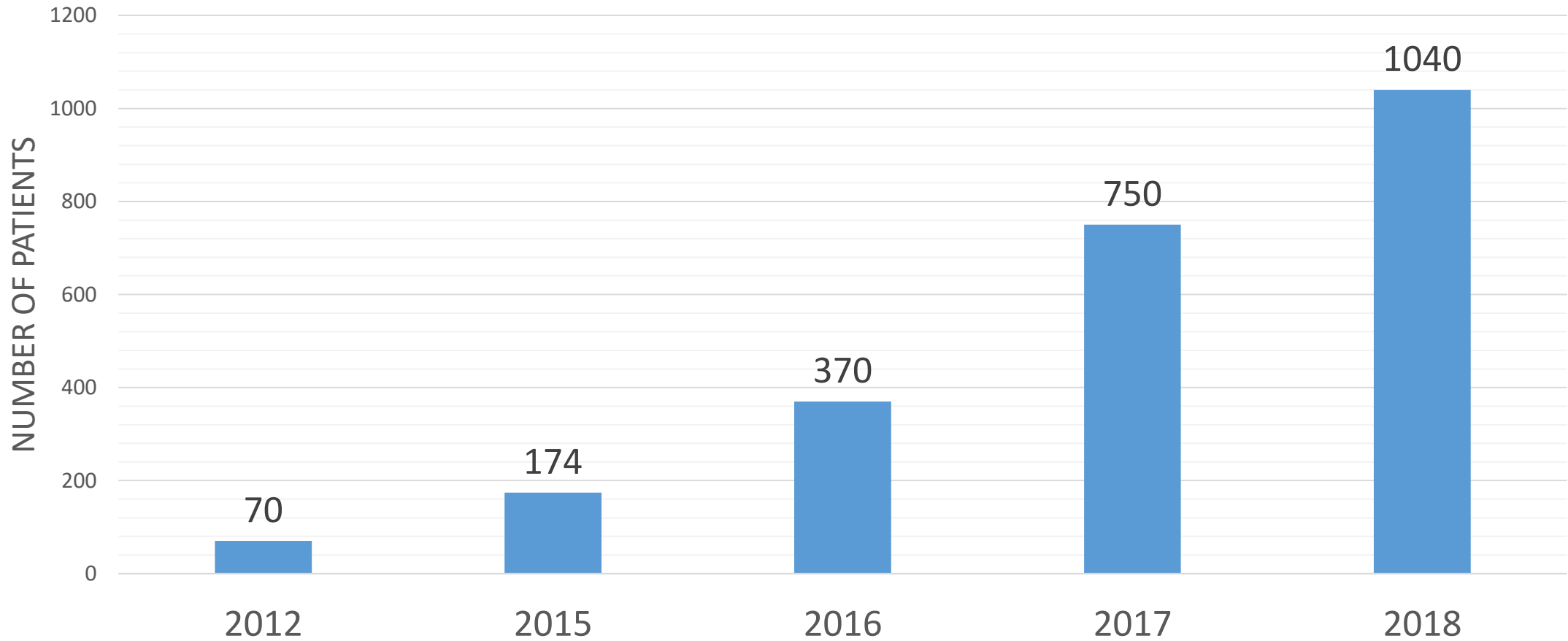
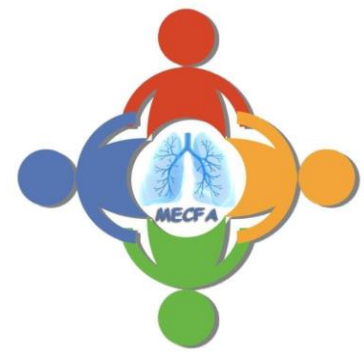
Total number of patients



- Number of patients in registry:888
- Number of patients who are waiting to register:152
- Total patients:1040



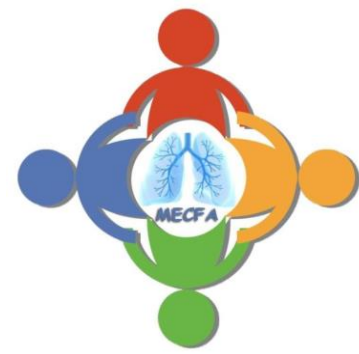
The number of patients has been register from 2012 to 2018





Iran CF Foundation(ICFF)

First CF registry annual data report Iran CF foundation(ICFF)



ORIGINAL ARTICLE

First Cystic Fibrosis Patient Registry Annual Data Report-Cystic Fibrosis Foundation of Iran

Asghar Aghamohammadi¹, Majid Keivanfar^{2,3}, Safoura Navaei⁴, Rohola Shirzadi⁴, Farzad Masiha⁵, Zahra Allameh³, Amin Heydari¹, Solat Eslami⁶, Gholamreza Azizi⁷, Mohsen Reisi^{2,3}, Mohammadreza Modaresi⁴

¹ *Research Center for Immunodeficiencies, Children's Medical Center, Tehran University of Medical Sciences, Tehran, Iran*

² *Department of Pediatric Pulmonary and Sleep Medicine, Imam Hossein Children's Hospital, Isfahan University of Medical Sciences, Isfahan, Iran*

³ *Child Growth and Development Research Center, Research Institute for Primordial Prevention of Non-Communicable Disease, Imam Hossein Children's Hospital, Isfahan University of Medical Sciences, Isfahan, Iran*

⁴ *Pediatric Respiratory and Sleep Medicine Research Center, Children's Medical Center, Tehran University of Medical Sciences, Tehran, Iran*

⁵ *Department of Pediatrics, Mazandaran University of Medical Sciences, Sari, Iran*

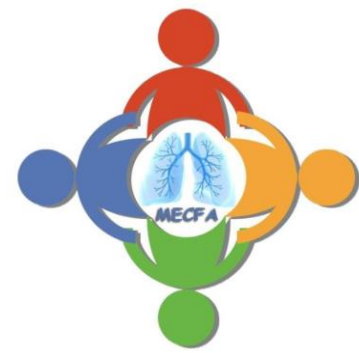
⁶ *Dietary Supplements and Probiotic Research Center, Alborz University of Medical Sciences, Karaj, Iran*

⁷ *Non-Communicable Diseases Research Center, Alborz University of Medical Sciences, Karaj, Iran*

Received: 01 Sep. 2018; Accepted: 14 Oct. 2018



Iran CF Foundation(ICFF)



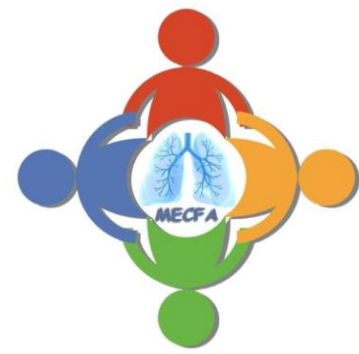
First annual report

- **LESS THAN 5% OF THE CYSTIC FIBROSIS POPULATION IS OVER 18.**
- **IN US** :MORE THAN **50%** OF THE CYSTIC FIBROSIS POPULATION IS **OVER 18.**
- **WE SUCCEEDED TO INCREASE NUMBER OF ADULT PATIENTS (>18) ABOUT 4% IN 4 YEARS.**

Percent of population	In the US(2018)	In Iran-2014	In Iran-2018
>18 years	54%	4%	8%
<18 years	46%	96%	92%

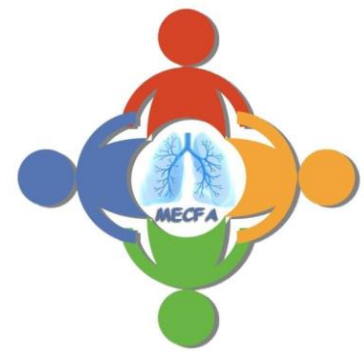


Iran CF Foundation(ICFF)



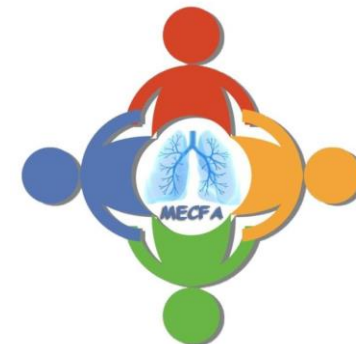
CF facilities at CMC

Infant and pediatric pulmonary Function laboratory



- We developed a modern and comprehensive pediatric pulmonary function laboratory and sleep center in CMC.





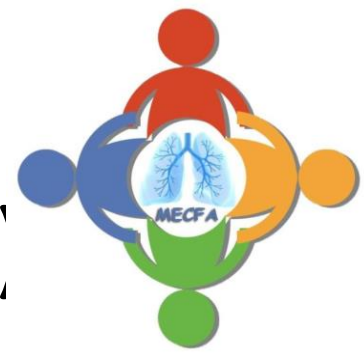
CF PULMONARY FUNCTION TESTS

various tests perform in our lab for infant, preschool and school age patients ,such as:

- **Multiple breath inert gas washout (Exhalyzer d - Lung Clearance Index: LCI)**
 - **FRC / LCI Infant (SF6-washout)**
 - **FRC / LCI Pre-School to Adult**
- **Spirometry**
- **Bronchial challenge with methacholine**
- **Lung volume measurements (Plethysmography & Gas dilution techniques)**
- **Lung diffusion capacity (DLCO)**
- **Impulse Oscillometry (IOS)**
- **CPAP/BIPAP Testing**
- **Exhaled Nitric Oxide (FE_{NO})**
- **Nasal nitric oxide**
- **Respiratory muscle Strength (PE_{max}, PI max)**
- **Cardiopulmonary Exercise Test (CPET)**
- **Six-minute walk test**



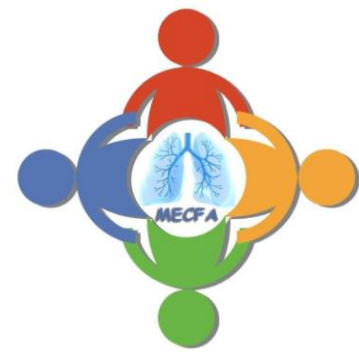
Exhalyzer-D lung Clearance Index-LCI (nitrogen washout)





Iran CF Foundation(ICFF)

lung volume measurement



plethysmography

gas dilution

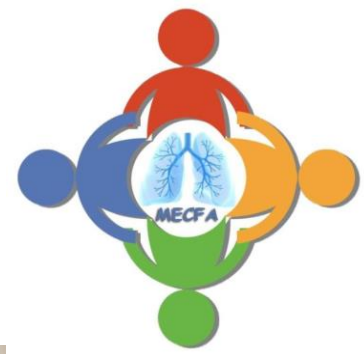
lung diffusion capacity





Iran CF Foundation(ICFF)

Cardio Pulmonary Exercise Test(CPET)





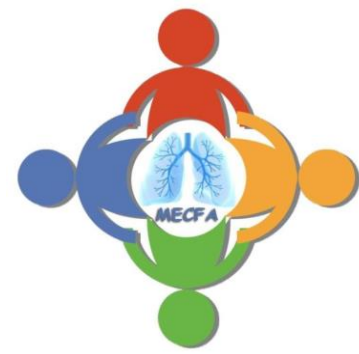
Iran CF Foundation(ICFF)

spirometry

FeNo

nasal NO

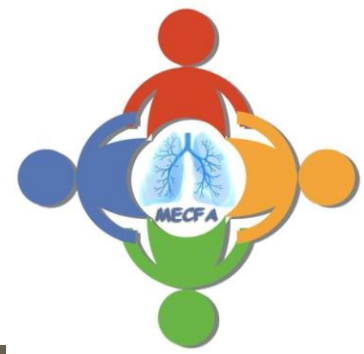
IOS





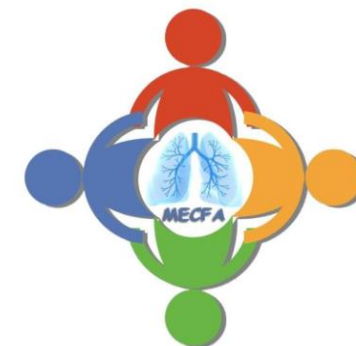
Iran CF Foundation(ICFF)

Sleep Laboratory



Our sleep lab, helps to diagnose over night hypoxemia in CF patients





BRONCHOSCOPY SUITE

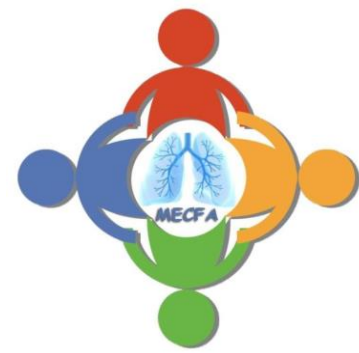
For the high risk infants and/or neonates with CF, if it is necessary the bronchoscopy will be done.





Iran CF Foundation(ICFF)

Iran CF Foundation(ICFF)

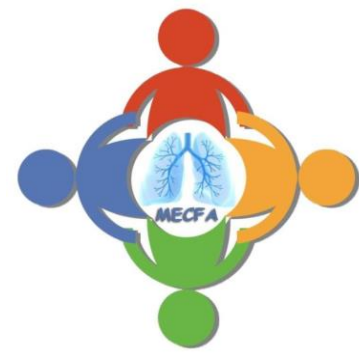


- The CF foundation(ICFF) of Iran was established by Iranian ministry of health in 2018
- Registered number:46060
- National code :14007998770
- The aims of the CF foundation are as follows:
 1. Collect the donations for CF patients
 2. Progress and development of research and investigation for treatment of CF patients
 3. Communicate with International centers that involved in all aspects of CF patients
 4. Consultation with Ministry of Health and Insurances for importing the required technologies and drugs into our country



Iran CF Foundation(ICFF)

Iran CF Foundation



Info@iranconf.com

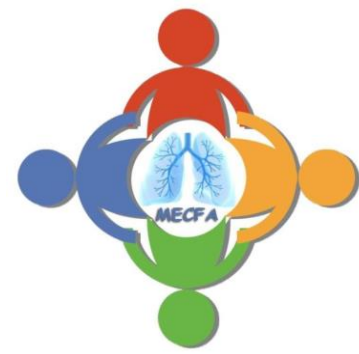


Iran CF Foundation(ICCF)
Reg Number46060



Iran CF Foundation(ICFF)

ICFF website objectives

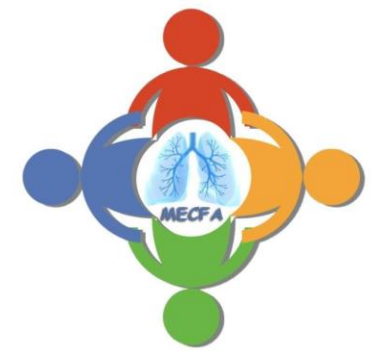


1. Online education of CF patients
2. Act as an official news outlet for CF patients
3. An easy access registry system
4. Online medication provider
5. Charity work

www.cfiran.com

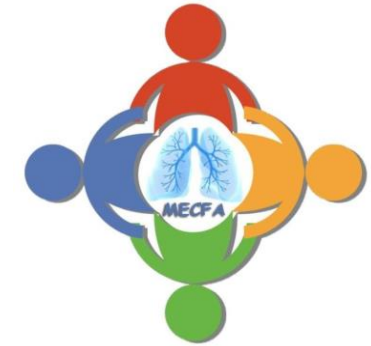
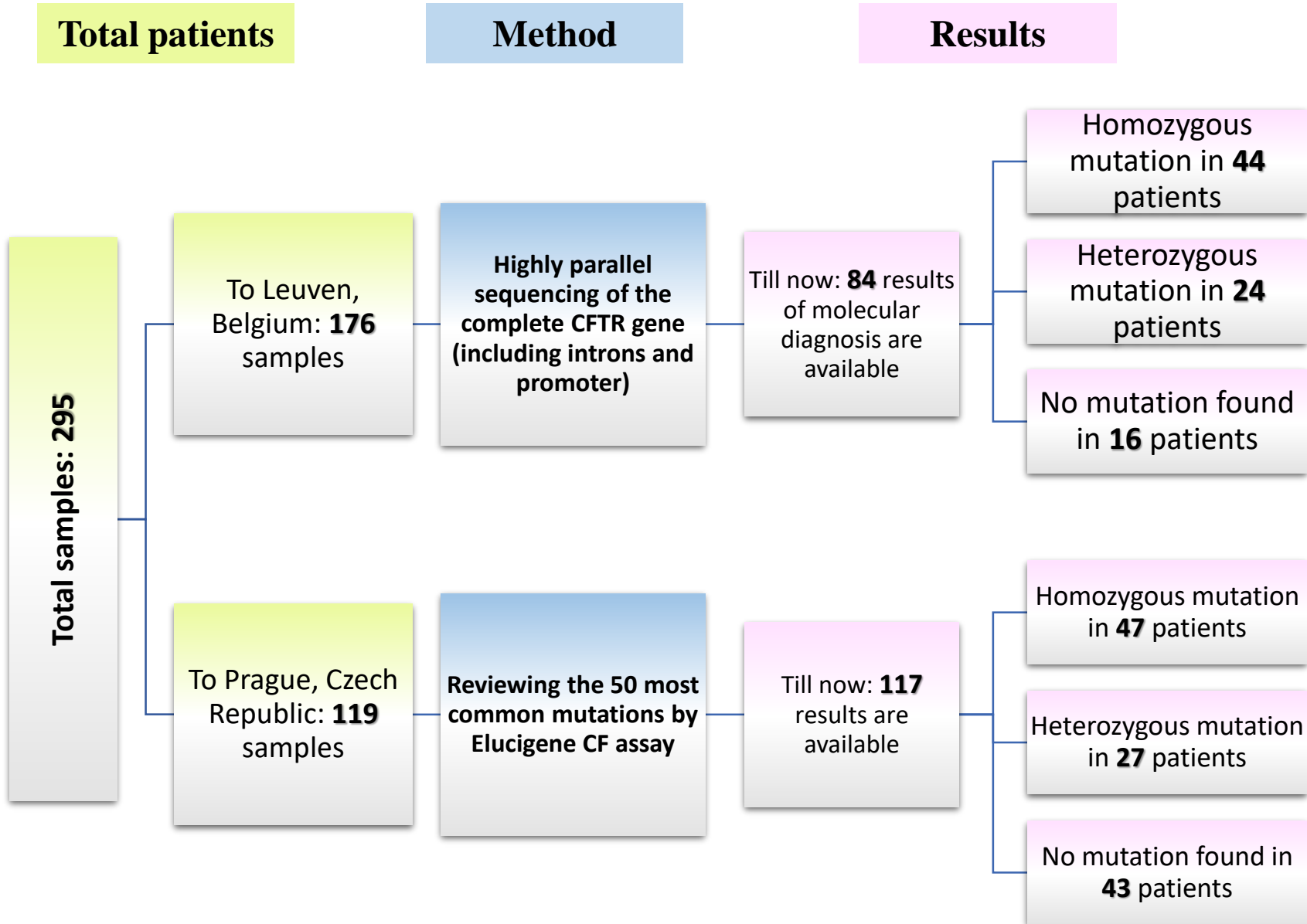


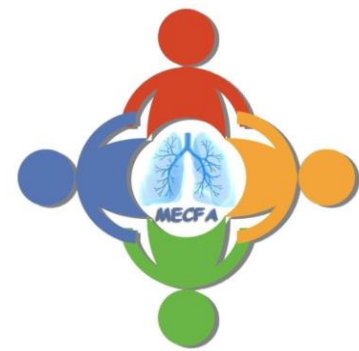
Iran CF Foundation



Cystic fibrosis (CF) genotyping project in Iran

**In collaboration with European Cystic Fibrosis Society
(ECFS) and MECFA**





	Definite molecular diagnosis (Till Now)	Percentage of molecular diagnosis	Most found mutation ($\Delta F508$)
Total	165 patient/401	45%	
Performed in Leuven	44 patient/84	52%	22%
Performed in Prague	47 patient/117	40%	52%
Performed in Iran	74 patient/200	37%	47%

- ✓ All of the found mutations have been confirmed/ will be confirmed by Sanger sequencing method or MLPA (in case of deletions and duplications)!

➤ Future plan:

NGS targeted sequencing for CFTR gene (all coding regions & introns) will be performed for those patients with no molecular diagnosis by the Elucigene assay



Iran CF Foundation(ICFF)

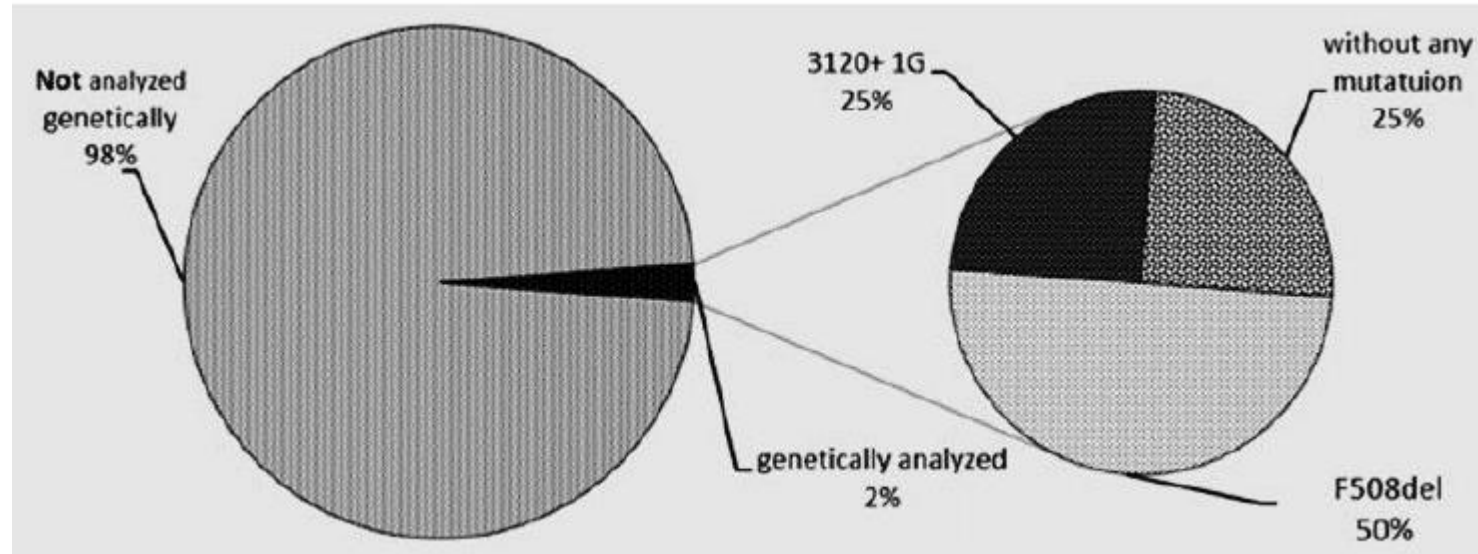
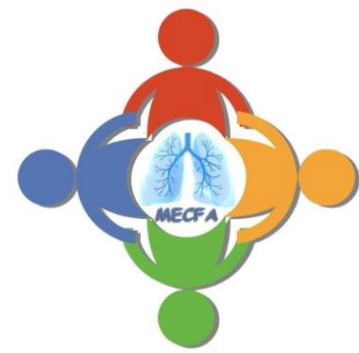
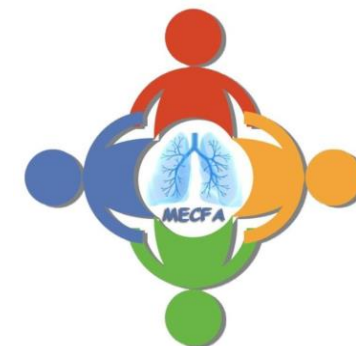


Figure 7. The frequency of genetic analysis and observed mutations in CF patients

Only **3 patients** with CF had a Genetic analysis until 2014

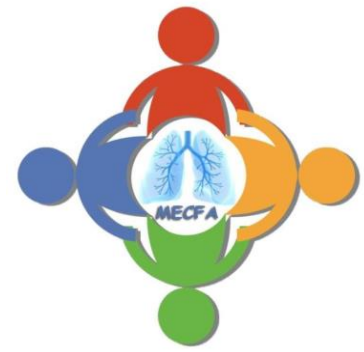
Now **165 patients** has a genetic analysis

The Storage of DNA samples in biobank



- We maintain 295 extracted DNA samples in biobank (patients & parents samples)

Social media of ICFF



- We use Telegram App
 1. to answer the CF patients questions by our CF expert team
 2. To add the new patients to CF registry
 3. To train the parents and patients

With more than 1000 members

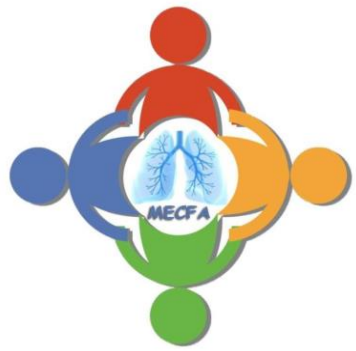
- No-cost
- simple color –code for multidisciplinary approach






Iran CF Foundation(ICFF)

ICCF telegram group



←  بنیاد سی اف ایران: سی ا...
1036 members, 69 online

Pinned Message ×
Dr.Modaresi Pediatric Pulmonologist: ...با سلام خ

You added Gholami Dr Spirometry

زه — Zohre — ره

Najafi Dr GI

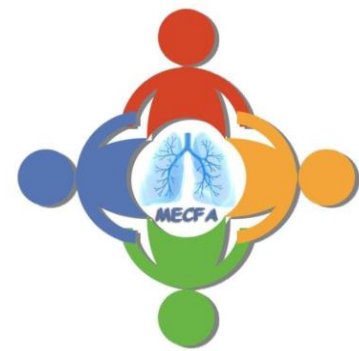
ازمایشات خوبست، معاینه باید بشود. با دو...
خانم دکتر توسط دکترای اورژانس
معاینه کردن ،،، همش خوب بود،،، گفتن
مشکلی نداره حتی سونو گرافیم نوشتن
برای روده اونم مشکل نداشت

2:02 PM



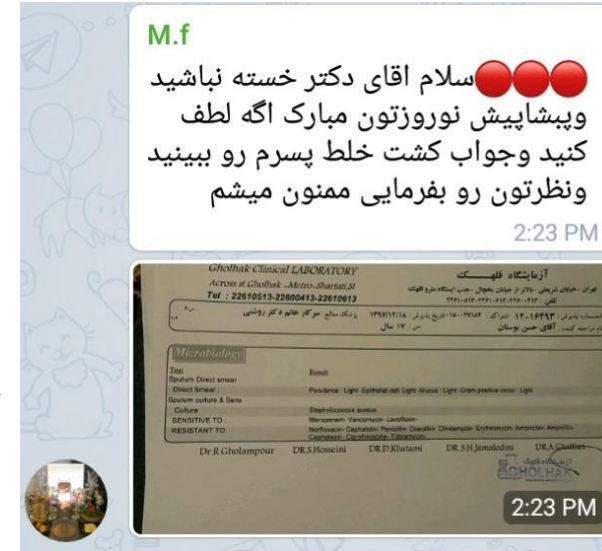
Iran CF Foundation(ICFF)

ICCF telegram group



simple color –code for multidisciplinary approach

Red color: pulmonary A&Q



Blue color: Gastro interstitial A&Q



زه —Zohre— ره

Najafi Dr GI

ازمایشات خوبست، معاینه باید بشود. با دو...

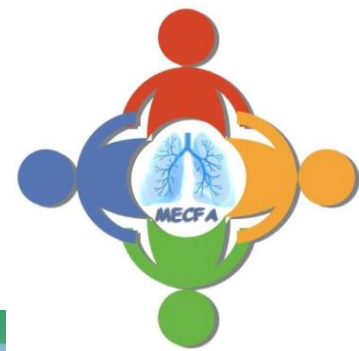
خانم دکتر توسط دکترای اورژانس معاینه کردن ،،،همش خوب بود،،،گفتن مشکلی نداره حتی سونو گرافیم نوشتن برای روده اونم مشکل نداشت





Iran CF Foundation(ICFF)

Conferences




29th
International Congress
of Pediatrics

CF Foundation

1st
International Congress of
Cystic fibrosis & Pediatrics
Respiratory Disorder

Topics:

- Organoid Technology
- Lung & GI Management
- Cell & Gene therapy
- New Scoring Methods of lung CT Scan
- Psychosocial Aspects
- Genetics

October 26 –27, 2017
Tehran–Iran

E-mail : pedcong@tums.ac.ir Website : www.iranped.ir
Toll : 982161472434 Fax : 982166949662
Telegram : @pedcong

**3rd Symposium on Stem Cell and Cell Therapies
in Lung Diseases**



سومین سمپوزیوم
سلول های بنیادی
و کاربرد آن در
بیماری های ریوی
دارای امتیاز بازآموزی


مقالات دانشجویی و دانش آموزی
پذیرفته می شود.

محورهای سمپوزیوم

پیوند سلول های بنیادی در فیبروز ریوی، افزایش فشار ریوی
پیوند سلول های بنیادی در بیماری های التهابی ریوی
کاربرد سلول های بنیادی در بیماری های صعب العلاج ریوی کودکان
کاربرد سلول های بنیادی در سیستمیک فیبروزیس
چالش های استفاده از سلول های بنیادی در بیماری های ریوی
مراقبت های لازم پس از پیوند سلول های بنیادی در بیماری های ریوی
جایگاه استفاده از سلول های بنیادی در عفونت های مقاوم ریوی کودکان
اخلاق در پیوند سلول های بنیادی

مکان:
بیمارستان
مرکز طبی کودکان
زمان:
۴ مردادماه ۱۳۹۷

وب سایت: www.pedlung.ir
شماره تماس: ۰۲۱-۶۶۹۲۹۳۳۴-۰۲۱ ساعت تماس: ۱۶ تا ۲۰
ایمیل: mimohseni.nure@gmail.com



30th
International Congress
of Pediatrics

CF Foundation

2st
International congress of cystic
fibrosis & Pediatric Orphan Lung
Diseases

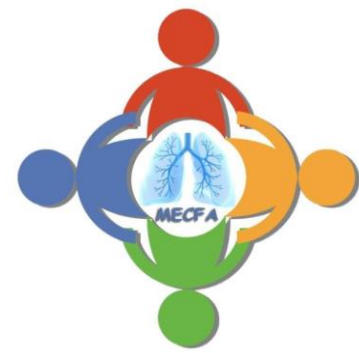
October , 2018
Tehran– Iran



E-mail : pedcong@tums.ac.ir Website : www.iranped.ir
Toll : 982161472434 Fax : 982166949662
Telegram : @pedcong



Iran CF Foundation(ICFF)



Conferences for *parents!*

با حضور فوق تخصصین و کارشناسان در مرکز طبی کودکان
دانشگاه علوم پزشکی تهران برگزار خواهد شد:

1st Parents Education Conference

موارد مورد بحث شامل:

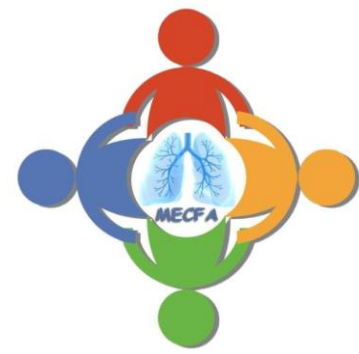
۱. نحوه برخورد با مشکلات ریوی بیماران سی اف
۲. چگونه برخورد با کاهش وزن بیماران سی اف
۳. چگونه برخورد با مشکلات گوارشی در بیماران سی اف
۴. نحوه تغذیه و تغذیه مناسب برای بیماران سی اف
۵. نحوه انجام فیزیوتراپی در بیماران سی اف

حضور والدین و بیماران بالای ۱۵ سال در همایش بلا مانع است
نحوه ثبت نام از طریق گروه تلگرامی سی اف و فردایی بهتر
از تاریخ ۲۰ لغایت ۲۲ بهمن ماه انجام می شود در ضمن ارسال تصویر کشت حلق
حین ثبت نام برای جدا سازی بیماران لازم و ضروری است

اولین همایش آموزش سراسری بیماری
سیستیک فایبروزیس
برای والدین:
زمان: ۲۸ بهمن ماه ۱۳۹۵

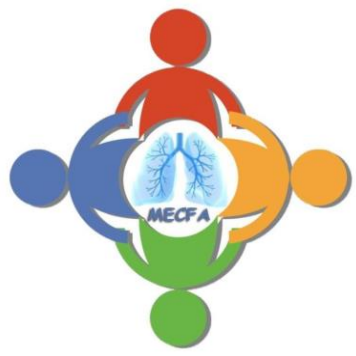


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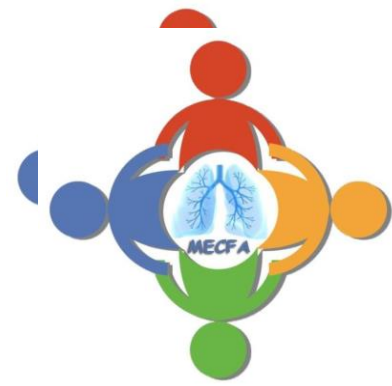


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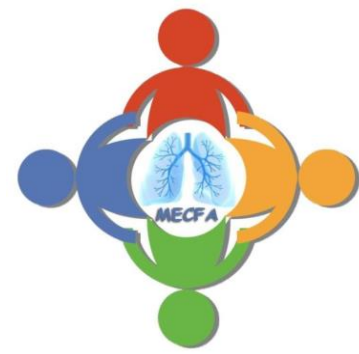
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OUR RECENT REASERCHES AND PROJECTS



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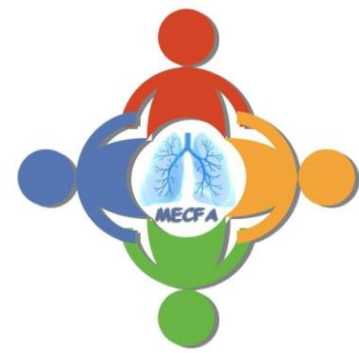


- Evaluation of correlation of Lung clearance index(LCI) and FEV1 in cystic fibrosis patients
- Provided by: Dr Rafizadeh(Respiratory disease fellowship)



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Cystic Fibrosis Patients' respiratory sound analysis



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Arezoo Karimizadeh

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Mohammad Koloshani



Multi-channel lung sound processing system

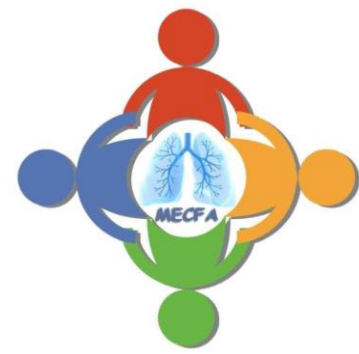


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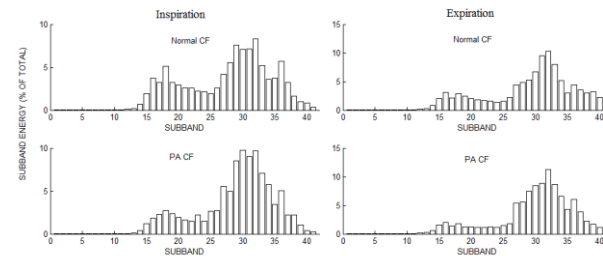
Infection Detection in Cystic Fibrosis Patients based on respiratory sound analysis(Accepted For Publishing)



- This device discriminates respiratory sound of CF patients by accuracy of about 90.3%.
- Which It helps us in rapid infection diagnosis.



Respiratory sounds



Computerized Time- frequency analysis



The proposed method discriminated respiratory sounds of PA CF from Normal CF patients by accuracy of about 90.3%.

Study of the therapeutic effects of Mesancymal Stem Cells in pulmonary infection of *Pseudomonas aeruginosa* in the Mouse Model



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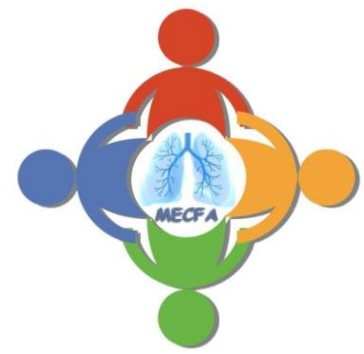


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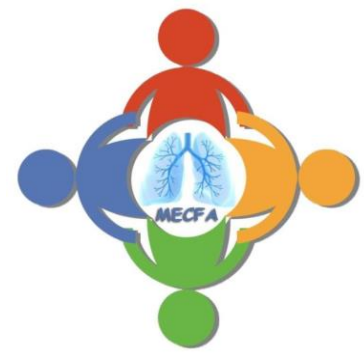
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Mesancymal Stem Cell a new therapy



- ✓ Evaluation and Isolation of *P. aeruginosa* from CF patients
- ✓ Design and construction of a chronic *P. aeruginosa* pulmonary infection in a mouse model
- ✓ Investigation of the therapeutic effects of Mesancymal Stem Cells in this Mouse Model





Current projects:

Association between Ergospirometry(CPET) and spirometry variables in pediatric patients with cystic fibrosis .

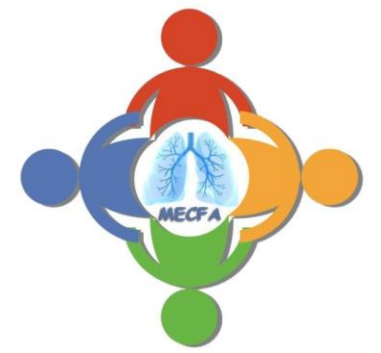


- Provided by: Sedigheh yousefzadegan
- Respiratory disease fellowship in Tehran university of medical science



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Current projects:

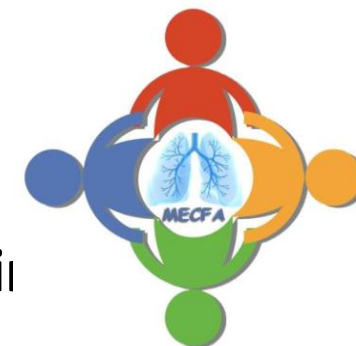


Study on sleep structure and polysomnographic respiratory markers in cystic fibrosis children

- Provided by: Mahdieh ghaempanah
- Respiratory disease fellowship in Tehran university of medical science



Project: Lung CT image analysis in CF patients



Objectives: Automatic scoring and monitoring of Cystic fibrosis patterns in lung HRCT images

Project Managers:



Pr. H. Abrishami Moghaddam (PhD)
K.N. Toosi University of Technology



Dr. S. M. Modaresi (MD)
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M. Mahdizadeh (MD)



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Z. Naseri (PhD)



F. Abdoli (MSc)



S. Sherafat (MSc)



K. Nezamabadi (MSc)



A. Fooladi (MSc)

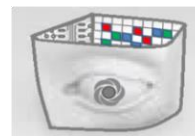
Partners and Sponsors:



K.N. Toosi
University of Technology



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MEDICAL SCIENCES



Machine Vision and
Medical Image Processing Lab

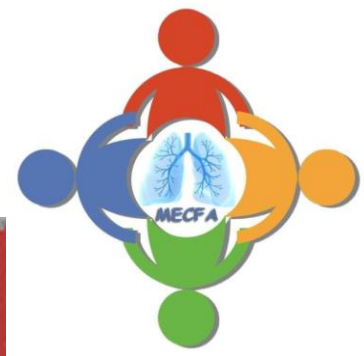


The Office of President
Vice-Presidency for Science and Technology
Iran National Science Foundation



Childrens Medical Center

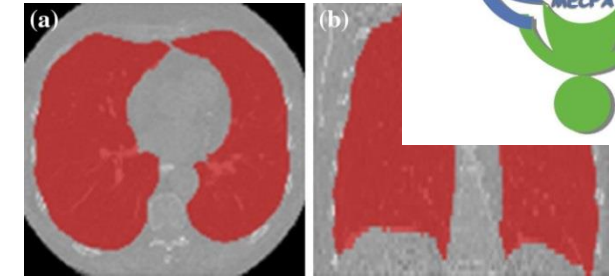
Project: Lung CT image analysis in CF patients



Achievements:

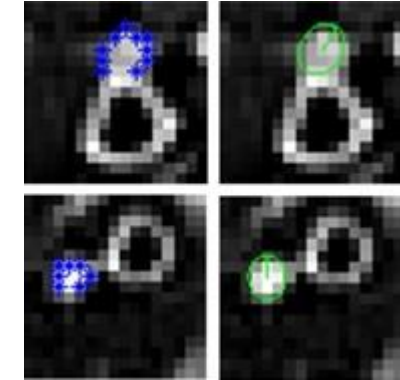
- **Advanced model-based lung segmentation algorithm from 3D CT images**

Nasari, Z., et al. A new model-based framework for lung tissue segmentation in three-dimensional thoracic CT images, *Signal, Image and Video Processing*, 2018.



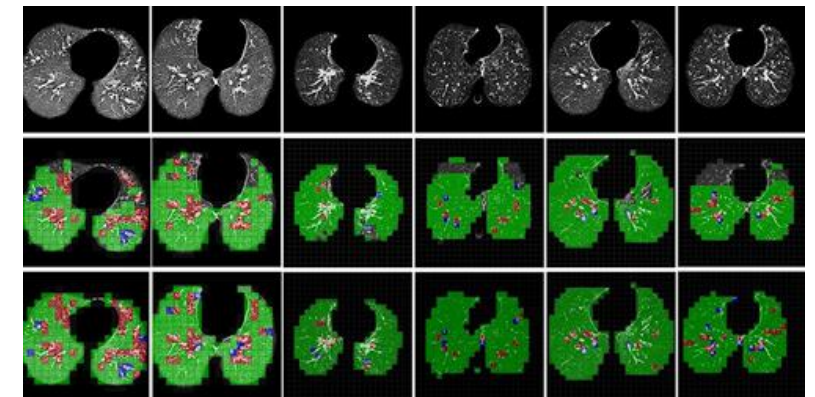
- **Semi-automatic airway and vessel characterization in bronchiectasis patterns**

Nasari, Z. et al. Semi-automatic Methods for Airway and Adjacent Vessel Measurement in Bronchiectasis Patterns in Lung HRCT Images of Cystic Fibrosis Patients, *Journal of Digital Imaging*, 2018



- **Automatic CF pattern classification in CT scans**

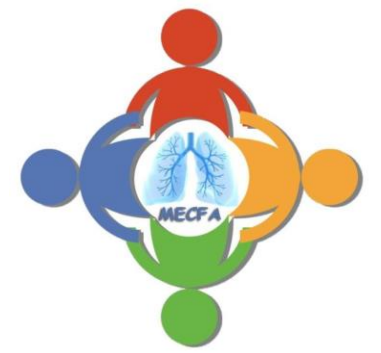
Nezamabadi K. et al. Lung HRCT pattern classification for cystic fibrosis using convolutional neural network, *Signal, Image and Video Processing*, 2019





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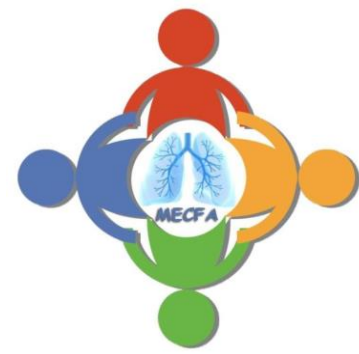
And now



We are planning the newborn screening of cystic fibrosis all over the country



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Thank you for your attention