

# MARMARA UNIVERSITY CYSTIC FIBROSIS CENTER TURKIYE



4 – 7 JUNE 2025  
MILAN, ITALY

48th EUROPEAN  
CYSTIC FIBROSIS  
CONFERENCE



**GAMZE TASTAN**  
**CF NURSE**



# TEAM MEMBERS

## ATTENDINGS

Bulent Karadag  
Fazilet Karakoc  
Ela Erdem Eralp  
Yasemin Gokdemir  
Pınar Ergenekon  
Ozge Kenis Coskun

## FELLOW

Seyda Karabulut  
Neval Metin Cakar  
Ceren Ayca Yıldız  
Eda Esra Baysal  
Fulya Ozdemircioglu  
Merve Akkitap  
Busra Demirel  
Ozgunay  
Emre Ugurlu

## NURSES

Burcu Uzunoglu  
Gamze Tastan  
Elif Degermenci

## DIETICIANS

Damla Kocaman  
Ece Bilen

## PSYCHOLOGIST

Hatice Kekec

## CHILD DEVELOPMENT SPECIALIST

Ayse Gumus

# PRESENTATION PLAN

PWCF IN TURKIYE AND OUR CENTER

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BASIC INFORMATION ON THE HEALTH CARE SYSTEM

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ROUTINE CLINICAL VISIT

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WHAT ARE THE DUTIES OF CF NURSE IN OUR CENTER?

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THE MODULATOR THERAPY EXPERIENCE OF MARMARA  
UNIVERSITY CF CENTER

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# CF PATIENTS IN TURKIYE

**ECFS PATIENT REGISTRY  
2023**



## CHILDREN (<18 years)

- 2255 Patient (82.54)

## ADULTS (>18 years)

- 477 Patient (17.46%)

2023

## CF PATIENTS IN MARMARA UNIVERSITY

**TOTAL  
PATIENT**

**442 PATIENT**

**ADULTS >18 YEARS**

**121 PATIENT  
(27%)**

2024

## CF PATIENTS IN MARMARA UNIVERSITY

TOTAL  
PATIENT

457 PATIENT

ADULTS >18 YEARS

146 PATIENT  
(32%)

**THERE ARE  
27 CENTERS  
IN TURKIYE**

**Two centers were following  
more than 200 patients**



**Specialized CF  
nurses were working  
in one-third of CF  
centers.**

# MARMARA UNIVERSITY CF CENTER



**4 ROOMS**

# BASIC INFORMATION ON THE HEALTH CARE SYSTEM AND HOW IT IS REIMBURSED OR FUNDED

- All Turkiye citizens, including pwCF, are born with social health insurance.
- All outpatient clinic expenses for pwCF are paid by the government (except modulator therapy).
- Health insurance also covers IV antibiotic therapy and intensive care services.
- Most medications are covered by the social health insurance



## NOT REIMBURSED

- Physiotherapy Devices
- Modulator Therapy

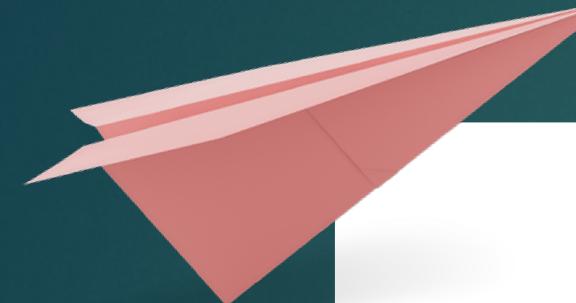
# MARMARA UNIVERSITY CF CENTER STANDARDS OF CARE

## ROUTINE

- CFTR Genetic Test
- Sweat Test
- Inpatient / Outpatient Care
- Nebuliser Therapy
- Spirometry
- Body Mass Index
- Sputum or Cough Swab For Microbiology
- Oxygen Saturation
- Lung Clearance Index

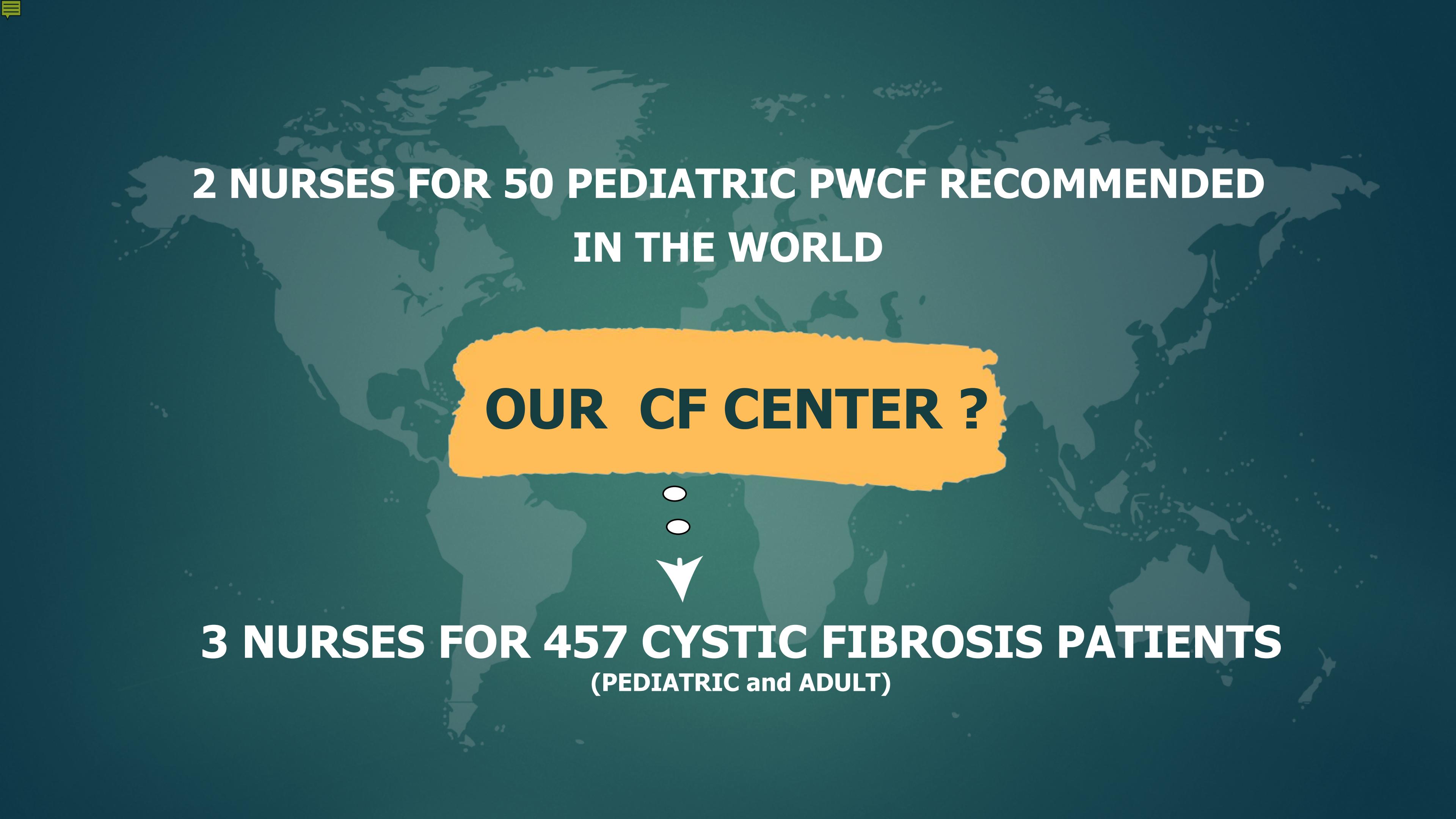
## IF NEEDED

- Oxygen Therapy
- Impulse Osilometry
- Bronchoscopy
- Lung CT
- Pulmoner Embolisation
- Enteral Feeding
- Nasogastric and Gastrostomy Procedures



**THERE IS NO SPECIFIC DEFINITION  
OF DUTIES AND RESPONSIBILITIES  
OF A CYSTIC FIBROSIS NURSE  
IN TURKIYE**





2 NURSES FOR 50 PEDIATRIC PWCF RECOMMENDED  
IN THE WORLD

OUR CF CENTER ?



3 NURSES FOR 457 CYSTIC FIBROSIS PATIENTS  
(PEDIATRIC and ADULT)

# WHAT DOES CF NURSING INCLUDE IN OUR CENTER, TURKIYE

Our most important duty is providing patients' medical records on time and regularly.

Data entry to the ECFS CF Patient Registry System has been made annually by the cystic fibrosis nurse since 2016 by the supervision of MDs.

# WORKLIST

## **ROUTINE CLINICAL FOLLOW-UP APPOINTMENTS**

- To organise routine clinical follow-up appointments
- To identify patients who do not come for regular follow-up and ensure them to come

## **CHECKING VACCINATION STATUS**

- To evaluate vaccination status and to apply the missing vaccinations

## **PFT**

- To perform pulmonary function tests and provide turbine cleaning and disinfection.

## **MEDICATION USAGE**

- To check the use of daily medications and give a written medication document to the patient or family.



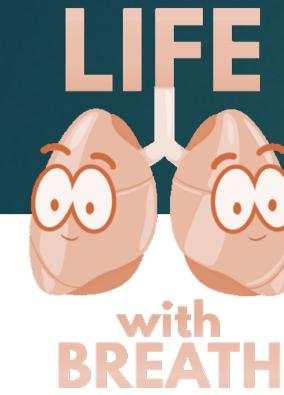
- We ensure pwCF communicate with other departments.



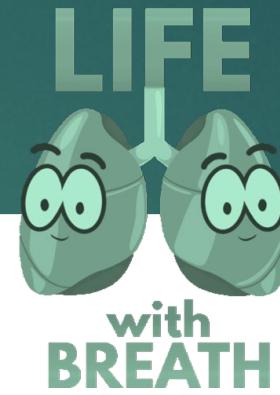
- We organize the appointments, especially for patients from other centers or countries.



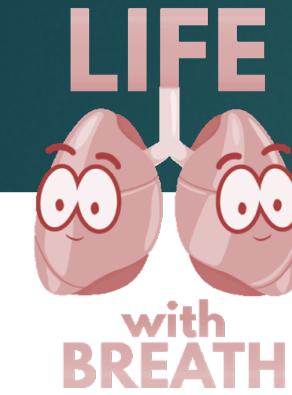
- We check the nebulizer devices of the patients whether if they are appropriate for their medications.



- After each outpatient clinical visit we check all the medical records and prescriptions



- We inform pwCF and the families regarding the next follow up visit



- If needed, we organize the multidisciplinary meetings to discuss the patient.



- Teamwork is vital to what we do.
- PwCF are constantly reviewed in our multidisciplinary meetings.

- **Failure to thrive**
- **Frequent exacerbations and hospitalizations**
- **Reduce in FEV1**

# PROJECTS



## Original Article

# Implementation of standardized cystic fibrosis care algorithm to improve the center data-quality improvement project international collaboration

Yasemin Gokdemir <sup>a</sup> , Ela Erdem Eralp <sup>a</sup>, Almala Pinar Ergenekon <sup>a</sup>, Cansu Yilmaz Yigit <sup>a</sup>, Muruvvet Yanaz <sup>a</sup>, Hakan Mursaloglu <sup>a, d</sup>, Burcu Uzunoglu <sup>a</sup>, Damla Kocamaz <sup>a</sup>, Gamze Tastan <sup>a</sup>, Ozge Kenis Coskun <sup>b</sup>, Amy Filbrun <sup>c</sup> , Catherine Enochs <sup>c</sup> , Sandra Bouma <sup>c</sup> , Courtney Iwanicki <sup>c</sup> , Fazilet K. Samya Z Nasr <sup>c</sup> , Bulent Karadag <sup>a</sup>

Pediatric Pulmonology

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## ORIGINAL ARTICLE

## Improvements in body mass index of children with cystic fibrosis following implementation of a standardized nutritional algorithm: A quality improvement project

WILEY



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ORIGINAL ARTICLE OPEN ACCESS

### Elexacaftor/Tezacaftor/Ivacaftor Treatment Accessibility and Mental Health: Reducing Anxiety in People With Cystic Fibrosis

Burcu Uzunoglu<sup>1</sup> | Merve Selcuk Balci<sup>2</sup> | Mine Kalyoncu<sup>2</sup> | Seyda Karabulut<sup>2</sup> | Neval Metin Cakar<sup>2</sup> | Ceren Ayca Yildiz<sup>2</sup> | Gamze Tastan<sup>1</sup> | Damla Kocaman<sup>3</sup> | Almala Pinar Ergenekon<sup>2</sup> | Yasemin Gokdemir <sup>a</sup> | Ela Erdem Eralp<sup>2</sup> | Fazilet Karakoc<sup>2</sup> | Bulent Karadag<sup>2</sup>

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**Keywords:** anxiety | CFTR modulator | cystic fibrosis | depression | ineligible

## ABSTRACT

Cystic fibrosis (CF) patients have a limited life expectancy, but significant medical advances now highlight the need for successful transition programs from pediatric to adult care. The implementation of a standardized nutritional algorithm has been shown to improve the quality of life and reduce hospitalizations in CF patients. This study aimed to evaluate the impact of the implementation of a standardized nutritional algorithm on the body mass index (BMI) of children with CF and to assess the mental health status of these patients. A quality improvement project was conducted in a single center, involving 100 children with CF. The project included the implementation of a standardized nutritional algorithm, which included the use of Elexacaftor/Tezacaftor/Ivacaftor (ET/TC/IV) and the reduction of anxiety levels. The results showed a significant improvement in BMI and a reduction in anxiety levels. The implementation of a standardized nutritional algorithm can improve the quality of life and reduce hospitalizations in children with CF. The results of this study can guide future policy for healthcare, nutrition, housing, and social support.

### Assessment of patients' baseline cystic fibrosis knowledge levels following translation and adaptation of the CF R.I.S.E translation project into Turkish

Merve Selcuk Balci <sup>1</sup> , Yasemin Gokdemir <sup>1</sup>, Ela Erdem Eralp <sup>1</sup>, Almala Pinar Ergenekon <sup>1</sup>, Cansu Yilmaz Yigit <sup>1</sup>, Muruvvet Yanaz <sup>1</sup>, Aynur Gulieva <sup>1</sup>, Mine Kalyoncu <sup>1</sup>, Seyda Karabulut <sup>1</sup>, Neval Metin Cakar <sup>1</sup>, Burcu Uzunoglu <sup>1</sup>, Gamze Tastan <sup>2</sup>, Damla Kocaman <sup>3</sup>, Ozge Kenis Coskun <sup>4</sup>, Ilknur Gorgun <sup>5</sup>, R Randall Messier <sup>6</sup>, Pamela I. Fazilet Karakoc <sup>2</sup>, Bulent Karadag <sup>1</sup>

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## Abstract

## Background

Cystic fibrosis (CF) patients have a limited life expectancy, but significant medical advances now highlight the need for successful transition programs from pediatric to adult care. The

### Associations between income level and health outcomes in people with cystic fibrosis in Turkey

Neval Metin Cakar <sup>a,1</sup> · Seyda Karabulut <sup>a,1</sup> · Mine Yuksel Kalyoncu <sup>a</sup> · ... · Yasemin Gokdemir <sup>a</sup> ·

Fazilet Karakoc <sup>a</sup> · Bulent Karadag <sup>a</sup> ... [Show more](#)

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### ► Highlights

- The first study in association between income level and health outcome among people with Cystic Fibrosis (pwCF) in Turkey.
- Highest insecurity in the social domain (68.5 %).
- It demonstrates the urgent need for support systems that meet both medical and social needs in resource-limited countries.
- Findings guide future policy for healthcare, nutrition, housing, and social support.

# THE MODULATOR THERAPY EXPERIENCE OF MARMARA UNIVERSITY CF CENTER

Has been used since June 2021

# MODULATOR THERAPY

- Since 2021, patients in Türkiye have been trying to get modulatory drugs by suing to government.
- All the medical documents needed for the court are prepared by the nurses.
- Since the drugs are given in 3-month doses, the documents are renewed every 3 months.

# OUR GOALS...

- To increase the level of knowledge of patients about CF
- To ensure compliance and follow-up with the routine visits
- To increase the level of knowledge about new treatments for CF
- Minimizing the rate of microbiological contamination and infection
- To ensure compliance in the transition from childhood to adulthood



THANK YOU