

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
Pinar Ergenekon
Ozge Kenis Coskun

FELLOW

Seyda Karabulut
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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

BASIC INFORMATION ON THE HEALTH CARE SYSTEM

ROUTINE CLINICAL VISIT

WHAT ARE THE DUTIES OF CF NURSE IN OUR CENTER?

THE MODULATOR THERAPY EXPERIENCE OF MARMARA
UNIVERSITY CF CENTER

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 Türkiye 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 Oscilometry
- Bronchoscopy
- Lung CT
- Pulmonary 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

PFT

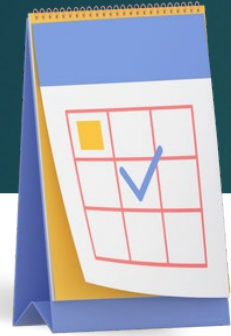
- To perform pulmonary function tests and provide turbine cleaning and disinfection.

CHECKING VACCINATION STATUS

- To evaluate vaccination status and to apply the missing vaccinations

MEDICATION USAGE

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



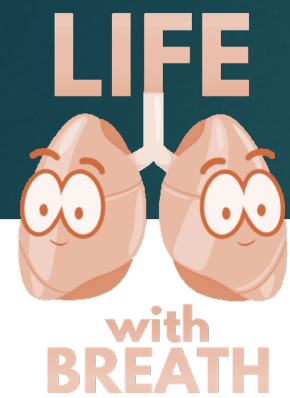
- We ensure pwCF communicate with other departments.



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



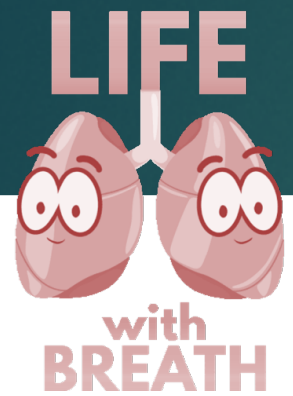
- We check the nebulizer devices of the patients whether if they are appropriate for their medications.



- 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^a  , Ela Erdem Eralp^a, Almala Pinar Ergenekon^a,
Cansu Yilmaz Yegit^a, Muruvvet Yanaz^a, Hakan Mursaloğlu^{a, d}, Burcu Uzunoglu^a,
Damla Kocamaz^a, Gamze Tastan^a, Ozge Kenis Coskun^b, Amy Filbrun^c ,
Catherine Enochs^c , Sandra Bouma^c , Courtney Iwanicki^c , Fazilet K.
Samya Z Nasr^c , Bulent Karadag^a

Pediatric Pulmonology

ORIGINAL ARTICLE OPEN ACCESS

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

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

ABSTRACT

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

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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

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ORIGINAL ARTICLE

 WILEY

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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 ndra Bouma MS⁴ | Courtney Iwanicki MS⁴ |
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Associations between income level and health outcomes in people with cystic fibrosis in Turkey

Neval Metin Cakar ^{a,1} · Seyda Karabulut ^{a,1} · Mine Yuksel Kalyoncu ^a · ... · Yasemin Gokdemir ^a · Fazilet Karakoc ^a · Bulent Karadag ^a ... 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