INDUS HEALTH NETWORK UK

IHHN Hosts Health Wise Session On

Cystic Fibrosis with International Experts

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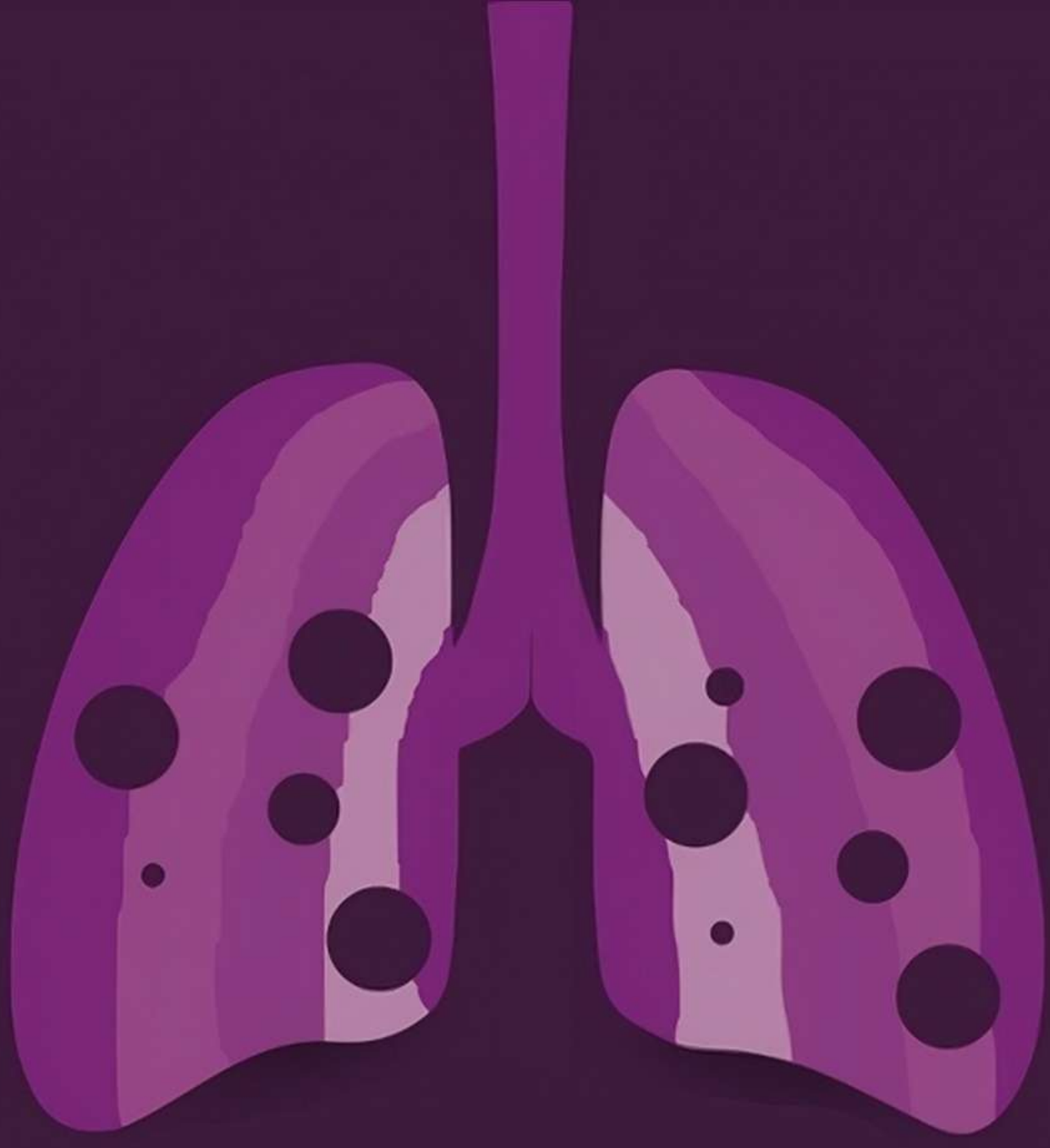


About Cystic Fibrosis

Cystic Fibrosis (CF) is a life-limiting inherited disorder caused by mutations in the Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) gene. It leads to the production of thick, sticky mucus that progressively damages the lungs, pancreas, and other vital organs.

Globally, the disease affects an estimated 150,000 people and has seen major advances in diagnosis and treatment over recent decades. However, in Pakistan, CF remains significantly underdiagnosed and underreported, largely due to limited awareness, lack of routine screening, and restricted access to specialised diagnostic facilities.

The Missing Numbers (Underdiagnosis)

There is currently no national cystic fibrosis registry in Pakistan, making it incredibly difficult to pin down an exact, verified prevalence rate.

Estimated vs. Actual Burden

While diaspora data suggests a baseline prevalence of

1 in 10,000,

domestic medical experts warn that the true internal burden in Pakistan is likely much higher due to underdiagnosis.

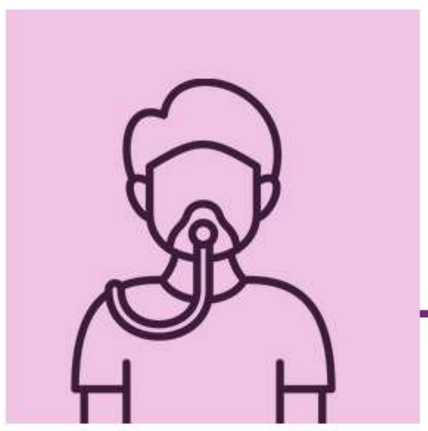
In contrast with Pakistan, the global statistics reflect that:

- Around 105,000 people are diagnosed with CF
- Researchers estimate a true total worldwide could range between 162,000 - 188,000 cases

The Diagnostic Delay

Because its symptoms mirror other highly prevalent regional healthcare issues, such as chronic malnutrition, tuberculosis, severe asthma, and recurrent childhood bronchopneumonia, CF is frequently misdiagnosed. Many children are treated purely symptomatically for standard respiratory or gastrointestinal infections, and a devastatingly high number of severe cases result in early infant mortality before a proper diagnosis is ever reached.

Whats stopping people from getting treatment:

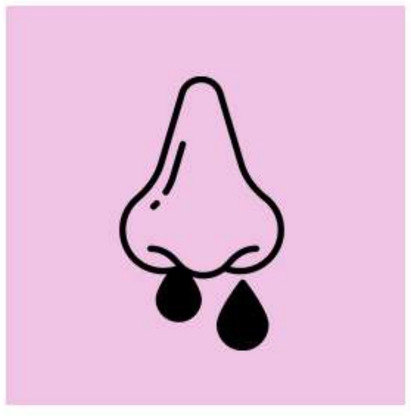


lack of specialised care

Lack of practitioners

Financial constraints

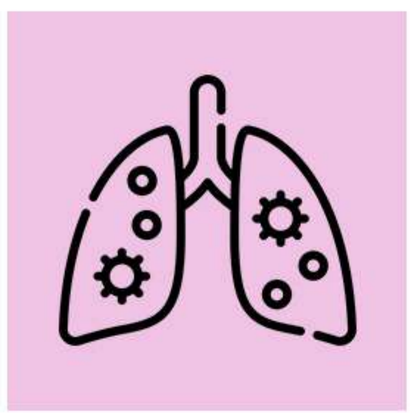
Cystic fibrosis causes thick, sticky mucus to block airways and digestive ducts. Common symptoms include a persistent cough with thick mucus, wheezing, frequent lung infections, and salty-tasting skin. Digestive signs involve poor weight gain despite a strong appetite, and bulky, greasy stools. Severe symptoms could lead to Male infertility. Cystic fibrosis affects multiple organs, and the severity or combination of symptoms can vary widely per individual.



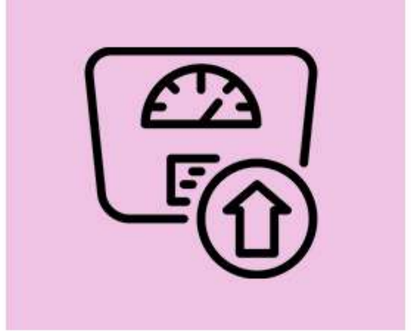
Thick Mucus

Persistent Cough

Wheezing



Lung infections



Poor Weight-gain

Male Infertility

Cystic Fibrosis Programme at IHHN

IHHN has revolutionised the local medical landscape with its groundbreaking CF Programme under the I HEAL Programme initiated by Dr. Muhammad Fareeduddin, which provides treatment for children and adults. Historically a neglected and misdiagnosed condition in Pakistan, IHHN tackled this crisis by launching the country's first comprehensive, multidisciplinary CF centre and partnering with Direct Relief to provide the life-saving gene modulator Trikafta entirely free of charge; a therapy that otherwise costs over USD 300,000 annually per patient. The programme provides universal, zero-cost care, including free on-site CFTR gene sequencing to 89 active patients who have already shown dramatic improvements in lung function, weight gain, and overall quality of life. IHHN has brought Pakistani patients into the global scientific conversation, alongside establishing a transformative, equitable international model for specialised respiratory medicine.

Dr. Muhammad Fareeduddin is the Head of Department (HOD) and Chair of Pediatric Services at IHHN in Karachi, Pakistan. He is a renowned paediatric pulmonologist and the first Pakistani physician to represent Pakistan at the North American Cystic Fibrosis Conference. In 2018, he inaugurated the I HEAL Programme at IHHN, expanding access to specialised care for patients with cystic fibrosis (CF) across Pakistan.

Scope of Services

Comprehensive Diagnostic Support

Provision of free access to vital, hard-to-access diagnostic tools, including sweat chloride analysis and specialised genetic mutation testing tailored to the local population.

Multidisciplinary "Under One Roof" Care

Integration of specialised teams across multiple fields to provide holistic patient management

Paediatric Pulmonology for lung health and infection control.

Dietetics and Nutrition for addressing severe malabsorption and failure to thrive.

Gastroenterology, Endocrinology, and Genetic Counselling.

Physiotherapy for specialised airway clearance techniques.

Psychosocial Support to assist families with the emotional burden of chronic disease management.

Free Life-Saving Medications

Routine supply of essential daily therapies entirely free of charge, including high-dose vitamins, specialised antibiotics, and Pancreatic Enzyme Replacement Therapy (PERT).

Advanced Modulator Access

High-income treatment barriers are broken down through international collaborations and donations, securing access to advanced gene-modulator therapies like **Trikafta**, a treatment that otherwise costs up to PKR 9,000,000 (USD 33,000) per month. Under this initiative, dozens of eligible paediatric patients in Karachi and Lahore receive this revolutionary treatment for free, showing dramatic improvements in lung function, weight gain, and quality of life.

Global Integration & Research

250+
patients screened for CF

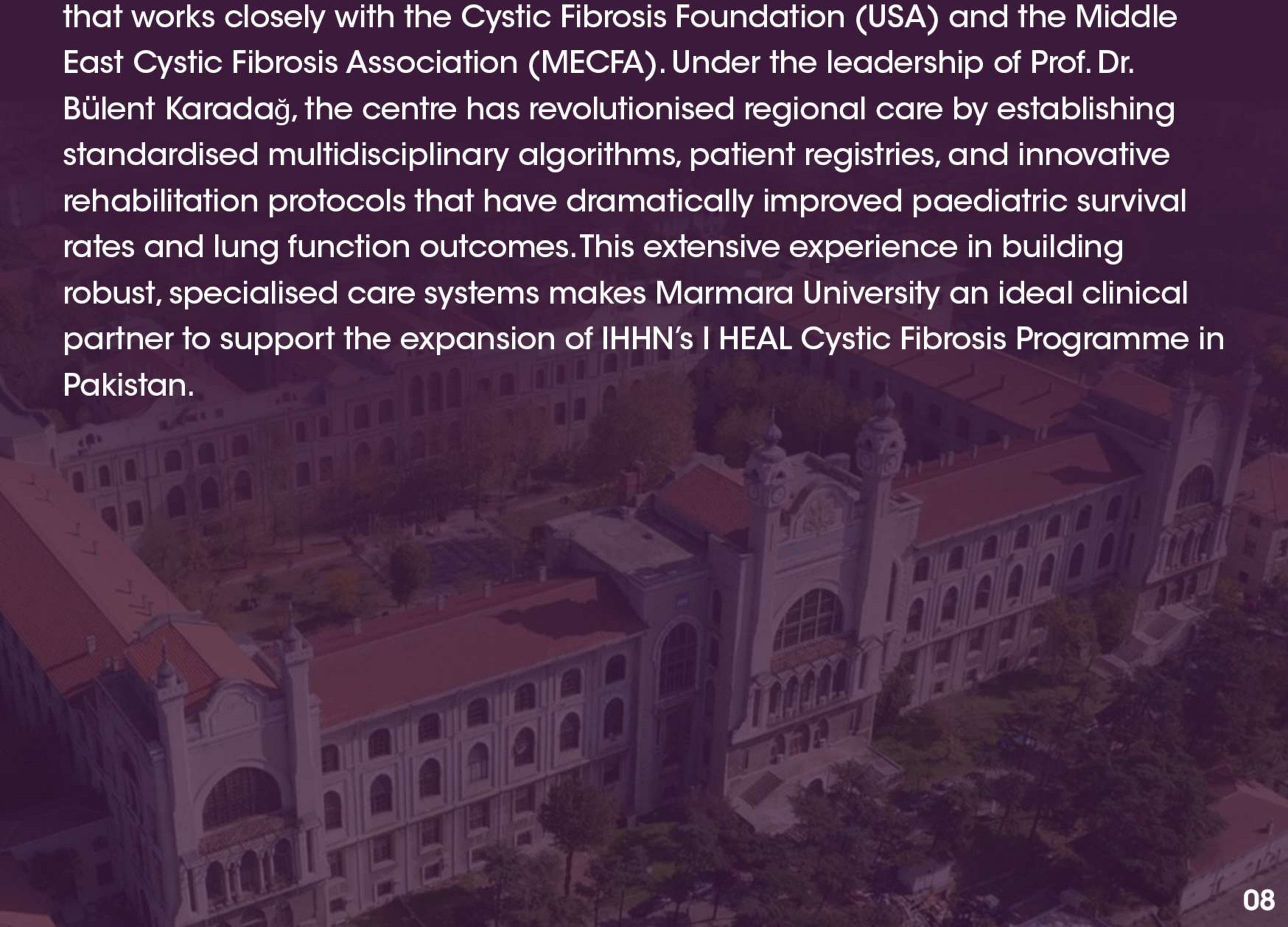
200
patients enrolled for Treatment

Through structured data collection, the initiative has successfully integrated Pakistan into the European Cystic Fibrosis Society Patient Registry, placing Pakistani genetic variants and clinical data on the global medical map.

International Expertise & Training

The international Cystic Fibrosis Training & Development Workshop at Indus Hospital & Health Network (IHHN) was led by a distinguished medical delegation from **Marmara University Hospital, Istanbul,** including Prof. Dr. Bulent Karadag, Prof. Dr. Yasemin Gökdemir, and Prof. Dr. Özge Keniş Coşkun. The event was hosted by Dr. Muhammad Fareeduddin (Head of Cystic Fibrosis, IHHN) and Dr. Zafar Zaidi (CEO, IHHN).

Marmara University (Istanbul, Turkey) is one of the country's oldest and most prestigious public research institutions, with its School of Medicine recognised as a global leader in respiratory medicine. The university houses the **Selim Çöremen Cystic Fibrosis Center,** an international centre of excellence that works closely with the Cystic Fibrosis Foundation (USA) and the Middle East Cystic Fibrosis Association (MECFA). Under the leadership of Prof. Dr. Bülent Karadağ, the centre has revolutionised regional care by establishing standardised multidisciplinary algorithms, patient registries, and innovative rehabilitation protocols that have dramatically improved paediatric survival rates and lung function outcomes. This extensive experience in building robust, specialised care systems makes Marmara University an ideal clinical partner to support the expansion of IHHN's I HEAL Cystic Fibrosis Programme in Pakistan.



Prof. Dr. Bülent Karadağ

Prof. Dr. Bülent Karadağ is a world-renowned paediatric pulmonologist and the Head of the Division of Paediatric Pulmonology and the Cystic Fibrosis (CF) Centre at Marmara University, Istanbul. He serves as the Chair of the European Respiratory Society (ERS) Paediatric Cystic Fibrosis Group and is a founding member and Vice-President of the Middle East Cystic Fibrosis Association (MECFA). A prolific researcher with over 179 scientific articles, his work focuses on asthma, cystic fibrosis, and bronchiectasis. He was awarded the prestigious Philip Hopewell Global Leadership and Research Prize by the American Thoracic Society (ATS) for his global contributions to respiratory medicine.

Prof Dr. Yasemin Gokdemir

Prof. Dr. Yasemin Gokdemir is a paediatric pulmonologist in Turkey's largest Cystic Fibrosis (CF) Centre at Marmara University, providing care for almost 500 CF patients. She has been working in the Clinical Trials Network Education Committee of the European Cystic Fibrosis Society since 2025. She has been elected Secretary of the ERS Paediatric Cystic Fibrosis Group for the upcoming term.

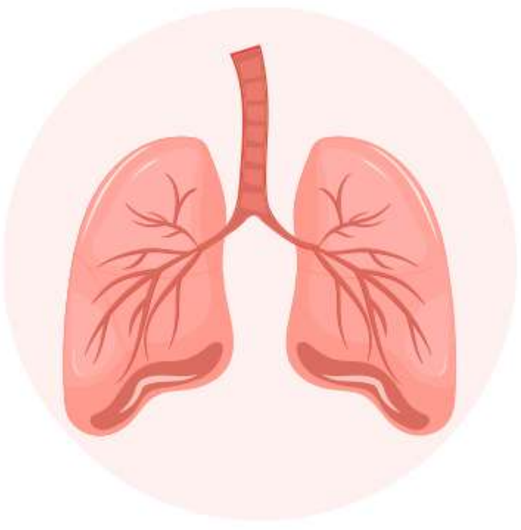
Prof. Dr. Özge Keniş Coşkun

Prof. Dr. Özge Keniş Coşkun is a physiatrist at the Marmara University Medical School. She has been working with the CF team at the Selim Çöremen Cystic Fibrosis centre for the past 10 years. She has conducted research in musculoskeletal involvement, airway clearance therapies, and exercise for patients with CF.

Core Training Pillars & Key Sessions

1. Acute Management and Breakthrough Modulators

- **Managing CF Exacerbations:** Prof. Dr. Yasemin Gokdemir led training on standardised, evidence-based protocols to rapidly identify, monitor, and treat acute respiratory episodes. The team focused heavily on how early, aggressive intervention directly shapes a child's long-term survival and preserves lung function.



- **The Modulator Frontier:** The session deep-dived into the clinical implementation and tracking of CFTR modulator therapies (specifically breakthrough treatments like Trikafta), discussing patient eligibility, response monitoring, and how these targeted gene therapies are actively shifting the disease from a fatal condition to a manageable chronic illness.

2. Clinical Therapeutics and Airway Clearance

- **Chest Physiotherapy & Inhalation Therapies:**
  Led by physiotherapy expert Prof. Dr. Ozge Kenis Coskun, this hands-on tracking focused on optimised inhalation techniques and mechanical airway clearance. Local teams practised specific chest physiotherapy regimens essential for moving the thick, sticky mucus characteristic of CF out of paediatric lungs.

- **Nursing and Nutritional Interventions:** Clinical modules led by the visiting faculty emphasised that survival depends heavily on specialised nursing and aggressive nutritional support. Training covered precise dosing protocols for Pancreatic Enzyme Replacement Therapy (PERT) and targeted Vitamin A, D, E, K supplementation to counteract severe malabsorption.

3. Data Systems and Global Research Integration

- **The Power of Patient Registries:** Prof. Dr. Bulent Karadağ conducted a core session on the strategic value of systematic data collection. He demonstrated how global patient registries inform health policy, optimise localised clinical decisions, and map specific regional genetic profiles.

- **Research Transference:** Prof. Dr. Gokdemir shared extensive published literature and clinical findings coming out of the mature Marmara University CF Centre, providing local teams with a blueprint for a highly active, research-driven clinical programme.

Activity Summary across the Three-Day Mission

Day 1: Foundation, Registry Frameworks, and Infrastructure Tour

- Conducted the official opening ceremony led by IHHN executive leadership and the visiting delegation from Marmara University, Istanbul, where guests were presented with traditional Sindhi Ajraks.

- Presented institutional overviews of the I HEAL Cystic Fibrosis Programme and reviewed systematic data collection strategies to drive clinical policy.

- Participated in an extensive hospital tour showcasing IHHN's state-of-the-art building, specialised patient care units, and modern diagnostic facilities.

- Reviewed diagnostic protocols, focusing on optimising sweat chloride analysis and addressing the limitations of Western genetic screening panels on local mutation profiles.

Day 2: Advanced Clinical Management and Hands-on Therapeutics

- Led deep-dive modules on identifying and managing acute respiratory exacerbations to prevent irreversible lung damage in paediatric patients.

- Conducted practical, hands-on workshops demonstrating specialised chest physiotherapy, mechanical airway clearance, and optimised inhalation techniques.

- Addressed nutritional rehabilitation protocols, focusing on precise dosing for Pancreatic Enzyme Replacement Therapy (PERT) and high-dose fat-soluble vitamin supplementation to combat severe malabsorption.

- Discussed the monitoring, eligibility criteria, and long-term tracking of advanced CFTR modulator therapies like Trikafta.

Day 3: Clinical OPD, Case Reviews, and Family Day Integration

- Joined the IHHN paediatric faculty on the front lines during a bustling Outpatient Department (OPD) clinic to evaluate multiple patients presenting with CF and exchange real-time insights.

- Facilitated interactive clinical case reviews, allowing local teams from IHHN, Aga Khan University (AKU), and Liaquat University of Medical and Health Sciences (LUMHS) to present complex patient cases for joint consultation.

- Hosted a transformational Family Day, creating a heartwarming space where families shared emotional testimonies about their battles with CF and the life-changing impact of receiving free treatment and Trikafta therapy.

- Concluded with a touching moment where paediatric patients expressed appreciation by presenting the Turkish doctors with beautiful, handcrafted gifts they made themselves..

Projected Impact, Concluding Proceedings, and Future Vision

The collaborative mission yields significant advantages for the local healthcare network and the broader medical community in Pakistan. On a clinical level, it equips multidisciplinary teams with evidence-based, international protocols for routine follow-ups, acute exacerbation management, and targeted nutritional rehabilitation, thereby establishing a standardised care pathway.

By extending this knowledge transfer to senior paediatric teams and registrars across major provincial networks, the workshop fosters a unified regional approach to managing complex genetic disorders. Furthermore, the training refines the monitoring and data-tracking infrastructure for patients receiving revolutionary CFTR modulator therapies, ensuring optimal clinical outcomes and safety tracking.

Over the long term, strengthening data integration into global registries helps place Pakistani-specific CFTR mutations on the international medical map, ultimately attracting global research partnerships and therapeutic resources to the region.

Following the conclusion of the academic, clinical, and patient family sessions, an official closing dinner hosted by the IHHN leadership provided an invaluable opportunity for informal exchange, strengthening professional and personal bonds between the Turkish delegation and local paediatric faculty.

The management and clinical teams express sincere gratitude to the visiting faculty from Marmara University for their exceptional dedication and shared expertise.The success of this international mission lays a strong foundation for sustained trans-institutional collaboration. IHHN looks forward to welcoming the delegation back for future advanced training iterations, clinical audits, and joint research initiatives as the programme continues to expand its reach across Pakistan.

Transformation of Lives under the I HEAL CF Programme

Diagnosed with Cystic Fibrosis (CF) a decade ago as an adult, Raheema faced the immense physical, emotional, and financial exhaustion of battling a rare genetic disease in Pakistan, where specialized care and life-saving treatments were historically out of reach. Supported by the unwavering love of her family, she fought through continuous infections and societal stigma until a life-altering turning point arrived through the Indus Hospital and Health Network's (IHHN) I HEAL CF programme.

Led by Dr. Muhammad Fareeduddin, this collaborative initiative provided Raheema and dozens of other patients with the game-changing gene modulator Trikafta entirely free of cost, a medication so expensive it is otherwise unattainable for even the wealthiest families. For Raheema, Trikafta was a miraculous awakening from a lifelong nightmare of chronic illness; it cleared the storm in her lungs, brought an end to seasonal pulmonary exacerbations, restored her appetite, and replaced constant fatigue with the long-awaited gift of taking a full, comforting breath and living a normal, hopeful life.

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