



CF Patients from the
Caritas Baby Hospital,
Palestine

MECFA
Annual Report
2018





"Many clinicians in the region are struggling to provide basic CF care against unjust odds. MECFA counters those odds by providing education for clinicians and allied health, guidance and support to improve CF care in pulmonology departments, access to necessary therapies and early diagnosis. Patients are the focus of every project we support, the end result has to be improved quality of life and life expectancy. "

Prof. Bulent Karadag, Turkey



Gaza CF patient with Prof. Karadag at the Marmara CF Center, Istanbul

CF care in the Middle East varies from country to country. In some countries we find a high standard of CF care available while in others, patients lack access to even basic care. In many countries there are no CF Centers with specialized clinicians and allied health professionals, adequate diagnostics or necessary medication and equipment. In 2018 MECFA launched the We Care Program to support members who are committed to improving health outcomes for patients in the Middle East.

The We Care Program supports members who are engaged in projects to establish;

- ✓ CF Centers staffed with trained interdisciplinary teams
- ✓ Access to basic CF medication and equipment
- ✓ Early diagnosis and genotyping of patients

EDUCATION

Education is KEY to establishing CF Centers staffed with qualified CF care professionals.

The We Care Program arranges training for clinicians, allied health and microbiologists at established CF Centers. Participants in the program return to their countries able to provide a level of care that helps CF patients live longer healthier lives.

DIAGNOSTICS

Early diagnosis means early intervention, decreasing long term costs of patient care. Understanding the genotype of patients in the region is important for the development of standardized care and detection of patients with mutations specific for the region. The program helps facilitate donations of diagnostic equipment, training and genotyping for diagnosed and suspected patients.

Essential Therapies

The treatment for CF includes daily medication and special equipment to manage the disease. Often these therapies are expensive, unavailable and overlooked by health authorities. Countries participating in the program will benefit from support lobbying health officials to provide basic medication and equipment.

MECFA is supporting Dr Nisreen Rumman to improve CF patient's health outcomes in Palestine

Program Objectives:

- 1) Improve standards of care, CF treatment and patient management at the Caritas Baby Hospital CF Clinic, Bethlehem
- 2) Improve standards of care, CF treatment and patient management at the Governmental Hospital in Gaza
 - Another CF team in Gaza needs to be trained (with continued supervision from the Caritas team)
- 3) Support lobby efforts to open access to essential drugs and equipment provided by the Ministry of Health under the national health plan.
- 4) Facilitate diagnostic equipment for the Government Hospital in Gaza



Caritas Baby Hospital CF team led by Dr Nisreen Rumman



Caritas CF Team visits Gaza CF patients



Caritas CF team visit to Gaza was supported by PCRF

CF in Palestine

There are over 300 Cystic Fibrosis sufferers in the West Bank and Gaza, predominantly preadolescent in age. In the last 3 years Dr Nisreen Rumman, lead CF pediatric Pulmonologist in Palestine has lost 4 patients to advanced CF and diagnosed 20 new patients. The Caritas Baby Hospital (CBH), is a small charity pediatric hospital located in Bethlehem where 120 CF patients are followed up by a small CF team consisting of a Pediatric Pulmonologist (Dr Rumman), dietitian, social worker and two physiotherapists. This team needs further training to improve their ability to provide quality care for patients. In addition, there are over 150 CF patients in Gaza. Those patients have even less resources than patients from the West Bank. Gaza patients were recently visited by Dr Rumman and her team from Caritas for assessment and genotyping to confirm diagnosis.

The Gaza Government Hospital CF team needs training and support to offer better care to patients. Essential therapies for daily management of CF are not all available and often only restricted access in West Bank and Gaza.

Currently in Palestine, patients have access to a few necessary therapies such as; bronchodilators, hypertonic saline and chest physiotherapy consisting mainly of manual percussion. Gentamycin IV form is used for inhalation, but there are no other inhaled antibiotics for CF available. In rare cases, families have been able to purchase hand held devices such as the flutter for airway clearance. Patients have access to Creon but no alternative enzymes.

In Gaza, access is often interrupted by the difficult political situation, stopping the flow of drugs and equipment to Gaza. But patients in Gaza are provided enzymes by the Palestine MoH.

Both West Bank and Gaza need sweat analysis diagnostic equipment and training to improve early diagnosis.



The Middle East CF Association is supporting a 2-year feasibility pilot program that aims to implement a state of the art, multidisciplinary CF Center in Istanbul, Turkey.

This pilot and feasibility project will establish a care center able to manage all clinical aspects of patients with CF, following best evidence-based care guidelines and adapting them to Turkey's setting. The program will train a multidisciplinary expert CF Team based in Turkey. The training will occur under direct and continuous supervision of the University of Michigan (UM) CF Center, both in the US and Turkey. The program will focus on quality improvement (QI) projects with the UM CF team working closely with University of Marmara (UoM) CF Center. Areas of QI work will include: improving BMI, improving pulmonary function testing, implementing Infection Prevention and Control (IP&C) in the center.

SPECIFIC OBJECTIVES

- ✓ To implement a state of the art, **multidisciplinary CF Center in Istanbul, Turkey**. This pilot and feasibility project will establish a care center able to manage all clinical aspects of patients with CF, following best evidence-based care guidelines and adapting them to Turkey's setting.
- ✓ To train a multidisciplinary expert CF Team based in Turkey. The training will occur under direct and continuous supervision of the University of Michigan (UM) CF Center, both in the US and Turkey.
- ✓ To significantly improve clinical outcomes of patients with CF

seen at the Center. We aim to improve the nutritional status measured by BMI% and lung function measured by FEV1% by FEF25-75%, respectively.

To focus on Quality Improvement work. The team at UM will work closely with Marmara CF Center to establish QI projects in the short term and in the long term to reach their goal of improving their care. Areas of QI work will include: improving BMI, improving pulmonary function testing, implementing Infection Prevention and Control (IP&C) in the center. Work started in a QI project addressing BMI using UM algorithms and protocols.

✓ To lead the subsequent implementation of a network of CF centers across Turkey. Once the pilot project has been consolidated, we will work with a second CF center in Turkey to implement the same approach we'll take with Marmara CF Center. That will be followed by working with the 2 centers and MoH to develop 5-8 regional CF Centers, thus creating the National CF Center Network in Turkey. The network will use Cystic Fibrosis Foundation standards for center accreditation in the US as the basis for standards for its accreditation standards in Turkey. To achieve in 5-8 years a median life expectancy approaching 30 years of age. This will be accomplished by cementing the National CF Center Network, using evidence-based, state of the art healthcare delivery, operating under strict quality improvement principles, ongoing multidisciplinary team training, and establishing a meaningful clinical research initiative.

*This pilot is supported in part by a grant from the Cystic Fibrosis Foundation. Prof. Samya Nasr, Director of the Michigan CF Center, Mott Hospital, Mich, USA and Prof. Bulent Karadag, Director of the Marmara CF Center, Istanbul, TUR are leading this 2 year feasibility pilot program.



The 2nd Middle East CF Conference took place in Izmir, Turkey and brought speakers and delegates from around the world together for 3 days to share knowledge.

The conference theme was “Developing CF care in the Middle East” and focused on building CF teams and US/European Standards of Care. In addition to a full Medical and Scientific program, the conference included allied health workshops and a family day organized in collaboration with the Turkish patient organization, KifDER.

The CF Foundation of the US was a supporter of the event and Dr Preston Campbell, President of the CF Foundation was the conferences Honorary Speaker.

Over 40 research abstracts were submitted with the top 10 chosen for oral presentation. The top 2 oral presentations were awarded 250 USD.

The Program.....

- * Challenges of CF Management in the Middle East: Introduction to MECFA
- * The Cystic Fibrosis Foundation – Introduction, progress, current program and opportunities for collaboration.
- * The European CF Society – Introduction, progress, current programs and opportunities for collaboration.
- * Establishing CF Centers, Standards and Challenges.
- * The role of registries in CF Care,
- * The History of CF In Turkey,
- * CF in Jordan, Present and Challenges,
- * Experience of CF in Oman – recent data overview
- * Nontuberculous Mycobacteria: pathogens or innocent bystanders?
- * Pseudomonas infection – Detection, approach and management
- * Current and future assessment of respiratory function in CF
- * Clinical experience of CFTR modulation and New Therapies in the Pipeline
- * Research and Clinical Trials – Middle East road blocks and potential
- * Social challenges of CF in Palestine: Perspective of a CF parent
- * Standards of care: newborn screening
- * Managing lung disease
- * End of life care
- * Psychosocial support
- * Genetics of CF in the Middle East
- * Nutrition in CF: Needs through different age groups
- * Ccost of illness analyses in cystic fibrosis
- * Lean CF care (cost effective care and less trouble for the patient)
- * Transition Intro Adult Care in CF patients
- Organoids, the road to personalized and optimal care for patients with CF.

Thanks to our international speakers!

Dr Preston Campbell, CFF President, USA	Nisreen Rumman, <i>Palestine</i>
Prof. Isabelle Fajac, European CF Society President, France	Basil Elnazir, <i>UAE</i>
Prof. Milan Macek, <i>Czech Republic</i>	Yazan Said, <i>Jordan</i>
Dimitri Declercq, <i>Belgium</i>	Prof. Ibrahim Janahi, <i>Qatar</i>
Ann Raman, <i>Belgium</i>	Asma Nuaimi, <i>UAE</i>
Prof. Samya Nasr, USA	Veronique Bontemps, <i>France</i>
Deniz Dogru, <i>Turkey</i>	Ilknur Görgün, <i>Turkey</i>
Prof. Elif Dağlı, <i>Turkey</i>	Ali M. Assiri, <i>Saudi Arabia</i>
Ihsan Jundi, <i>Jordan</i>	Sharifa Al Assiry, <i>Saudi Arabia</i>
Sumaya Al Orami, <i>Oman</i>	Hussein Alkindi, <i>Oman</i>
Prof. Bulent Karadag, <i>Turkey</i>	Kahled Baqais, <i>Saudi Arabia</i>
	Harry Heijerman, <i>Netherlands</i>
	Hanneke Eyns, <i>Belgium</i>



Christine Noke, Dr Preston Campbell, CEO of the CFF and Prof. Ibrahim Janahi discuss supporting CF research and clinical trials in the Middle East.



MECFA Research group headed by Prof. Ibrahim Janahi

Working to support and advance research and clinical trials in the Middle East

In 2018 MECFA supported research through cash awards for the top two abstracts submitted at the MECFC 2018

Top Abstract Winner

MOLECULAR ANALYSIS OF CYSTIC FIBROSIS PATIENTS IN WEST BANK, PALESTINE,
Hilal Abu-Rmaileh, Palestine

2nd Top Abstract Winner

EVALUATION OF SUBCLINICAL ATHEROSCLEROSIS DEVELOPMENT IN CHILDREN WITH CYSTIC FIBROSIS,
Gökçen Kartal Öztürk, Turkey

In 2019 MECFA will work to support Quality Improvement (QI) projects

Projects considered for support should aim to achieve one or more of the following:

- Improve pulmonary function
- Improve Nutrition and BMI
- Implementing infection control measures
- Screening for mental health for patients and family
- Organizing and structuring the CF clinics:
 - Pre-clinic huddle, using pre-clinic survey that patients/parents complete,
 - Post clinic review
 - Reviewing patients in a monthly staff meetings



Hilal Abu-Rmaileh



Prof. Janahi presents CF Research in the Middle East at the MECFC 2018



Gökçen Kartal Öztürk

Financials

OVERVIEW

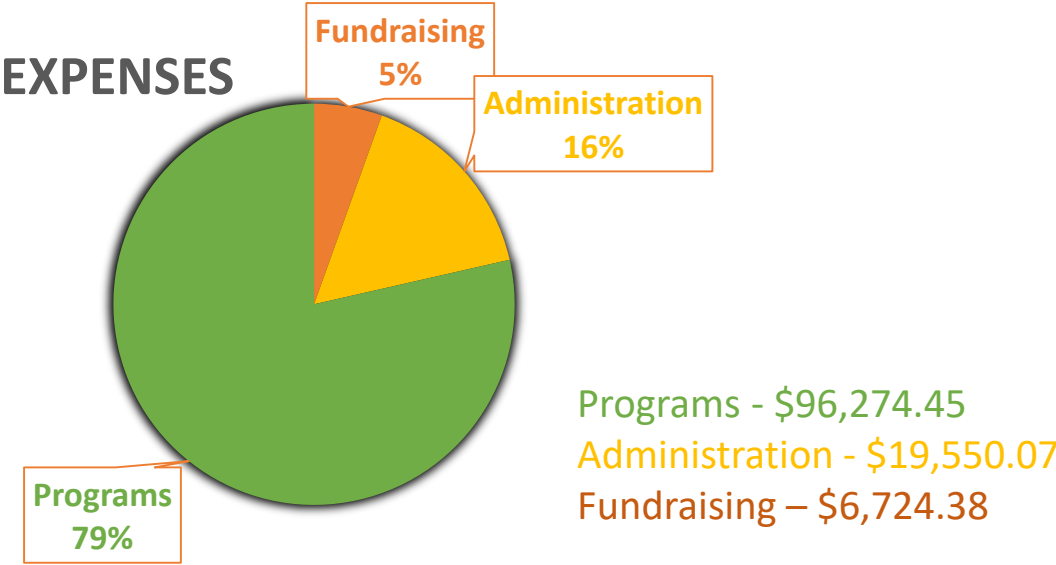
Jan 1 – Dec 31, 2018	
Cash Inflow	\$152,104.02
Cash Outflow	\$150,659.40
Net Cash Change	\$1,444.62
Ending Balance	\$1,444.62
Total For All Accounts	\$561,272.16

MECFA is supported through grants, events and public donations

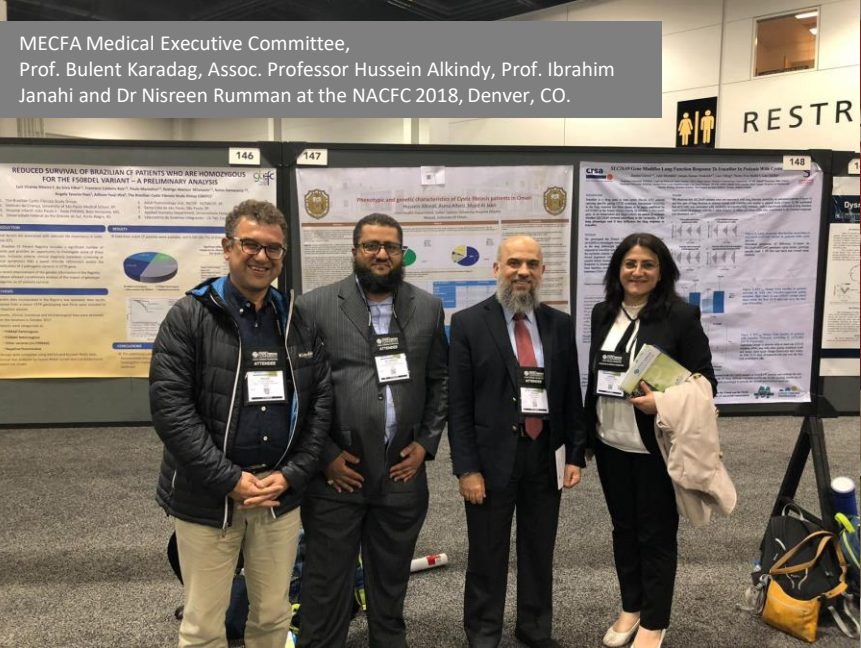
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MECFA Medical Executive Committee, Prof. Bulent Karadag, Assoc. Professor Hussein Alkindy, Prof. Ibrahim Janahi and Dr Nisreen Rumman at the NACFC 2018, Denver, CO.



MECFA CEO, Christine Noke and Executive Assistant, Sebnem Tuna at the Turkish Pediatric Pulmonology Conference 2018, Istanbul Turkey.



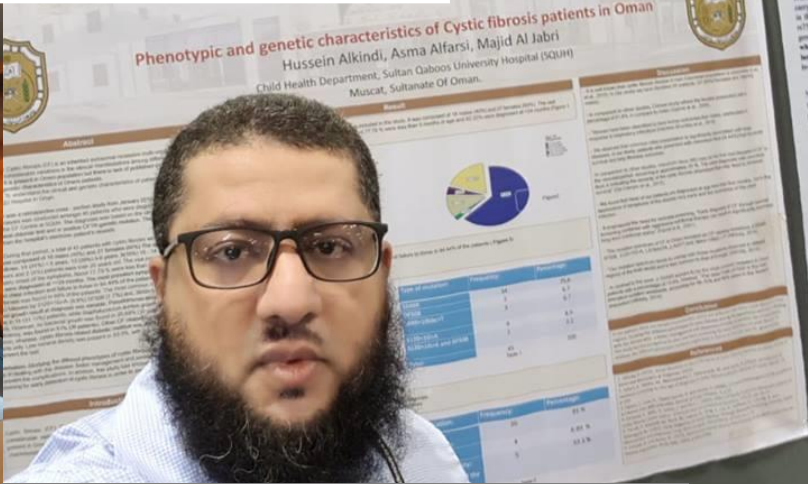
MECFA team at a 2 day working session in Doha, Qatar hosted by Prof. Ibrahim Janahi.



MECFA Medical Executive Committee and Staff
www.mecfa.org



MECFA team at the European CF Conference 2018 with Dr Preston Campbell, Dr Bruce Marshall and Dr Albert Faro from the CF Foundation.



Assoc. Prof. Hussein Alkindy with his abstract submission at the NACFC 2018, Phenotypic and genetic characteristics of CF patients in Oman.



MECFA team at the NACFC 2017 with Dr Preston Campbell.